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ABSTRACT

The study examined the social realities of hyperactivity through over 600 interviews with parents, teachers, and physicians. Interviewers sought to analyze the interactions of medical, educational, and familial social systems regarding diagnosis and treatment of hyperactive children. Three questions were focused on: beliefs and attitudes of physicians, teachers, and parents concerning hyperactive children; role perceptions of teachers, parents, and physicians; and modes of social systems interaction in treatment. Interview schedules were developed, refined, and administered along with questionnaires. Findings are discussed in terms of prevalence of hyperactivity (substantially lower than comparable findings in the literature); parents', teachers', and physicians' perceptions about the diagnosis and treatment of hyperactive children (including monitoring of children being treated with stimulant medication and the social psychological context); differing beliefs about and attitudes toward hyperactivity and stimulant medication treatment on the part of physicians, parents, and teachers (reflecting differences among social systems); the children's attitudes, perceptions, and experiences (including an overall positive view toward their medication); and parent, teacher, and physician roles in caring for hyperactive children (including disagreement over major responsibility). Analysis of dimensions of inclusion, dominance, and legitimacy in roles of parents, teachers, and physicians reveal areas of tension and incoherence in the three social systems. Policy implications are noted regarding the controversy over hyperactivity and its treatment and social forces which hamper policy development. Extensive appended material include sample forms and data tables as well as responses from child interviews. (CL)

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FINAL REPORT

PARENT, TEACHER AND PHYSICIAN IN THE LIFE OF THE HYPERACTIVE CHILD: THE COHERENCE OF THE SOCIAL ENVIRONMENT

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PARENT, TEACHER, AND PHYSICIAN
IN THE LIFE OF THE HYPERACTIVE CHILD:
THE COHERENCE OF THE SOCIAL ENVIRONMENT

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CHAPTER ONE

THE SOCIAL REALITY OF HYPERACTIVITY

The woman, in her mid-thirties, seemed tired yet determined. Though not eloquent, she had an ample store of colorful and powerful phrases with which to relate her story. She spoke with intensity, smoking cigarette after cigarette and displaying an eagerness to tell us about her child and her life.

She told us her story, a freewheeling account which we came to see as a dramatic prototype of the more spartan and sanitized accounts we would encounter in structured interviews during the later part of the research. The words of this parent provide a better introduction to the issues and controversies of hyperactivity than would a scholarly, dispassionate preamble.

Her account began with an answer to a question about the origin of her concern about her child:

Us: Now, when and in what way did you come to the realization that there might be some sort of problem?

Parent: Oh, about three months I would say....
...To start with he never slept more than two hours--ever--from the time we brought him home from the hospital. Rocking the floor with him would temporarily pacify him but, as soon as you stopped rocking, he would start.

He was getting more than enough food for his size...he just didn't seem to want to take any more, but he still did not sleep. And this was around the clock. I mean, by the time he was six months old he had never slept for more than two hours at any given time..Absolutely nothing held his interest for more than five minutes maybe--maybe--and then you really had to work at it you know.

Needless to say by the time he was a year old and I had not had more than two hours sleep myself at any given time I was a basket case. I allowed for colic; I allowed for spoiled; I went through the crying routine to let them cry it out--nothing worked.

All the time I was questioning the doctor at his monthly checkups. ...The frustrating part was that I was given all this: "Well you had him late in life and you have older children that's like four adults in the house." "He's very spoiled, you're just not firm enough, you're too nervous,

you're making a mountain, you know." By the time the kid was a year old I really thought that I was a mental wreck and causing all this hassle.

So then I began to hear--I didn't read anything, I had never heard of this before--but I began to hear things about some kids are born this way, some kids are this way, it's a sickness of some sort and you should ask your doctor about it.

Us: Do you remember where you heard this?

Parent: Well, like from friends. I have a girlfriend...that had a kid who was just all over the house all the time. Morning, night and noon, you know, and she got medicine for him. ...So anyway, I began to ask the doctor about it and I was constantly given this: "There's nothing wrong with the kid, it's you, you know," just constantly. Well, by the time he was 18 months old I mean, you know, when I did sleep I slept sitting up because then I didn't sleep even as sound as, however sound mothers sleep, which is not very, because I mean, you know, with a foot and a half of snow if he got up at two in the morning and decided to go out and check on the dog, he would.

He's very very bright...but he just--so this went on and again I began questioning the doctor. So I took him in for his two-year checkup. I got hyper myself and I said: "I know there is something wrong I don't care what it is. I just feel I have to know so I can deal with it and towards it." So he said: "Well, you know, the kid's hyperactive is probably all that's wrong. There's nothing really bad with him. It's mostly with you but if you want me to give something I will."

I said: "He picks up a toy and if he can run with it he'll take it. If he can't, he'll leave it and that's all he does is run. He screams for food. I put him in his chair. He won't eat. He screams to be down. The kid was two years old and weighed 22 pounds. He was a minute. So anyway he said: "I will give you a prescription." And I said: "Well, what is it?" He said: "It wouldn't mean anything to you." But he said give him a whole pill as soon as you get the prescription. "You'll get it this afternoon, won't you?" And I said yes. So I got the prescription and I gave him the pill at two, no it was about three. And by six, I thought the kid was active before he got on the medicine, you know, and he was just--he just tore--he didn't

run anymore, he just tore around the house.

But anyway, so at 6:30 I gave him his second pill. Now this was a 5 milligram pill of Ritalin so he had had about 10 milligrams in about 5 hours. For the next 12 hours he did nothing but move his hands, his feet, his arms and twitch his whole body--and not talk anymore but just incoherently mumble.

I called the doctor and he said well, it takes a period of time to adjust to his new medicine. And I said well, you know, what is this medicine? "What is it doing to him? He's not calming down if that's what it's supposed to do." "Well, it takes a while for his system to adjust to it." Well, this was about 3 o'clock in the morning and I began to think he was having some kind of a interaction to this medicine...So anyway he calmed down and I gave him a pill in the morning and I--it just started all over again. So I didn't give him a pill at noon and I called the doctor.

Well, I waited two days for him to call me back so I did not bother to give him any medicine during this time--which I told the doctor and he immediately chewed me out for it. "You mothers ask for pills and then you don't follow through with the directions and you wonder why you don't get results, you know." I--...the son of a bitch, you know, that's what he is. I can't help it. He's a pediatrician but he's a son of a bitch. "We'll cut the pill in half and give him that and see how it works."

So I did this for about two weeks. I did not notice--I just did not notice a change. I didn't notice any improvement whatsoever, and I just had this awful feeling I was harming him more than I was helping him and I just was not having any communication with the doctor at all and I just did not know where else to go and getting into a new doctor is just unbelievable.

In the popular literature, the parent - particularly the mother - of the hyperactive child is frequently perceived as negatively as our respondent was by her first pediatrician. T. A. Vonherhaar in his article, "Chaining Children with Chemicals" (1975) says:

Other studies concern the child's mother, who for various reasons, may be unable to cope with her own problems and who may not have wanted a child in

the first place. She is unable to manage ordinary infantile behaviors such as crying, soiling diapers, and other typical demands on her. The resentment and guilt may be perceived by the child, and he may panic. His behavior becomes a symptom of the immaturity and anxiety of the adults around him. The inadequacies of the parents and the teachers are projected on the child, who pays the penalty by being drugged into submission. (p. 17)

This parent does not deny the possible accuracy of her pediatrician's and T. A. Vanderhaar's assessment. Rather, she is concerned with the consequences of the condition being overlooked because of disagreement about the causes.

Parent: I was totally unfamiliar with any kind of drug. I just knew nothing about it, and I said: "Well, you know, if it is me, fine!" But I said "I don't feel it's fair to cheat the child and I feel he's being cheated. He is not having a normal childhood."

In her desperate attempt to find a solution, she was both willing to assign the blame to herself and to take any steps necessary to deal with the consequences. Her unsatisfactory experience with drug treatment led her to discontinue it and, eventually, to renew her efforts to obtain help.

Us: What was it that stopped you in your dealing with these [pediatricians]?

Parent: I dropped his medicine. Now that was at two years or shortly after and I--I just struggled through the next year, there's no other word for it. Now, when I look back...it was extremely hard. It was hard. That's all I did for the next year and then I think it was approximately, I'll say in February. He must have been three or fairly close to it. Dr. Marcus did a preventative medicine show on channel 3 dealing with the hyperactive child and ...I had no idea who he was or that he was a practice or nothing...So, you know, and at this point again I'm---help! And I said, "I cannot do this alone any more." I need help and so she [a friend] said she knew the name of a woman in Kalamazoo who could help me.

So I called Kalamazoo and I'm going on about the problem and yes, they have a fantastic program and so forth and lo and behold we get to the ages--they don't take care of little children. They help big people. So she gives me the name of another woman. So I call her. Yes, they take care of

children, yes at that age, yes they help parents. We go through this some more. We get the mailing address. Oh, oh, Kalamazoo county and Van Buren county, I'm screwed again. So then they give me the number of this mental health clinic. I call there. Believe it or not it was still wrong. That's the adult place. They give me the number of the place which is six miles from my back door that takes care of children. So I call there and I explain it again. Yes they can help me, yes, they decide from talking to me that I need and David needs help immediately. They will call me--this is I think on a Monday--and they will call me by Friday. Needless to say I lived on my phone.

Us: Were these calls all on the same day?

Parent: Yes.

Us: One call after another?

Parent: Right. That is an experience in itself....So where did I go? Okay, so they tell me--I wait all week. They do not call me. What do I do? I called back. Well, they're very busy and they have a waiting list because they are in the process of moving into this new building so I proceed to beg, which is not my nature, but I'm desperate. So they have a staffing meeting on Tuesday and they will present it then and present the problem--how desperately I need help and maybe someone will be willing to take on an additional load to get me going. So I call on Wednesday. "Please, didn't something happen last night? Nothing. They have me on a waiting list. I will be contacted definitely within two weeks. I said, "I have a party line. If it's busy will you keep trying?" "Yes." "Sometimes I go to the store but I'm not gone long. Will you try again?" "Yes." A month later I still had not been contacted. I called again. They were totally unaware of anything. You know--by now it's like the first of March--I forget it, you know. "To hell with you." "You sons of bitches talk but you don't care."

So I thought about this doctor, you know, and my neighbor had--I told her I had heard this--I said, "Boy, I wish I could find a doctor like that." She said: "He is a doctor." "He's a pediatrician in Kalamazoo." And I said, "Oh, you're kidding." She gets her phone book out and she says, "See?" I called, you know, "Can I get in? Please!" "No.

We take no new patients and we couldn't possibly give you an appointment for four months." "Oh, I can't wait that long. I am desperate. I don't know where else to go. Please!" "Well, if you call your regular doctor or your child's doctor and ask for a referral it's a very simple procedure. We will take him probably within a week or two." My mind has never been able to accept how they adjust that or whatever, but I was not going to question at this point so I call. They tell me, "Call your doctor, the nurse will answer or the receptionist. Simply tell her you want a referral. They will call you back with an appointment." So I call my doctor--David's doctor--Dr. Skipper. The girl answered and obviously they'd never been requested--a referral has never been requested because--it just blew her mind. And I said, "Well, I understand this is a very simple procedure. You just send them the general information." "You'll just have to talk to the doctor. I wouldn't dare release anything to anyone without the doctor's okay." You know, what is this shit, you know? At this point I think they're crazier than I am. They just don't know it. So the doctor comes on the phone, unfortunately, Dr. Skipper. "Why do you want to go to this other doctor? What's the problem? I'm his doctor." "Yes I know it but I want to find out--I think he may be hyperactive. This doctor seems to deal with this. I'd like another opinion." The doctor says, "I told you what was wrong with the kid. Why can't you just accept that?" And I said, "Dr. Skipper, please don't take it personally, I would simply like another doctor's opinion." The doctor said "Well you can have the damn thing then I'll get it out. I'll get it out this afternoon."

I think it was the next morning Dr. Marcus's office called me, and I think March 9th was probably the day the world began for me, because that's the day I came to Dr. Marcus. He walked into the office. He took one look at the kid. He took one look at my husband and I and he said, "I know just how you feel. Most of the time you fight to keep him from flushing himself down the damn toilet." And you sit there and you think I can't believe somebody really knows what's going on. He prescribed Ritalin and I told him then. "You know, that is what he was taking. I really don't want him to take that again." "Well," he said, "how much was he taking?" And I proceeded to tell him and he said, "My god, a two year old, that's way too much medicine." Here the kid was taking 15 milligrams at two and he's four now and only takes ten.

As a result of this visit to the physician the child was placed on a drug regimen at a lower dose level. The parent's response to the physician was strongly positive. He provided her with the first respite she had experienced in her two years with her child.

At another point in the interview we focused her comments on the present situation.

Us: What is he like at the present time in the house? You described the way he was back then when there was no medication, but how would you describe his behavior at the present time?

Parent: I would say normal--compared to my two other children. My two other children were what I would term not hyper, but active children. ...They got up at 7 in the morning and they played all morning and washed their grubby little hands. Up and play real hard until suppertime and play after supper and take a nice warm bath and jump into jammies and bedtime story and hugs and kisses and into bed. David is not quite like that. He gets up in the morning...and the first thing he does when his feet hits the floor is start to, you won't say scream, but yell. "I want my breakfast. I want my breakfast, hurry right now, right now." And you take him right into the kitchen. You put his breakfast right in front of him...as soon as he has it he stops yelling. He proceeds to eat. Some days he'll have two or three bowls (of Rice Krispies or Sugar Frosted Flakes) and when he's finished, I mean finished--he's done, forget it, and then he gets down. He may talk to you a few minutes, he may wander around, he may play with the dog.

Us: When does he take his medication?

Parent: Immediately. I mean, I put his breakfast there and setting it down I'm putting the pill in his mouth...(he) takes his half a pill and that's it.

Us: How often would you say you forget the afternoon pill?

Parent: I never forget it. I never forget it. I could almost--I could set the clock within a half hour of just watching David.

In spite of her (eventually) positive experience with medical help and medication, the respondent has misgivings about the

use of the prescribed medication, Ritalin. Her quandary is that the medication seems to be effective, no other good options have appeared, but she knows that Ritalin is a psychoactive drug. She feels that it may be a potentially dangerous or harmful drug.

Parent: I've had many qualms about Ritalin because I've read things about it and again, I guess all doctors are just human beings. Dr. Marcus thinks Ritalin is a lifesaver and thinks it's a kind of wonder drug for hyper children. So when you talk to him about getting addicted or some of the drawbacks that you read about--I don't want to screw up a decent relationship, you know, by bringing in other things. I was that desperate for help.

Us: How concerned are you about the medication he is taking?

Parent: Well, I resent that he has to take medicine. I really resent that. I read things about Ritalin, well just kind of, you know...I can't really say I've read anything about it but there seems to be this Ritalin it's, you know, so terrible and they always stick to this drug on this kid--that's the kind of thing I've read you know, but I can't say what I've read. Parents don't realize that maybe the kid is calm now but he'll be a basket case for the rest of his life, you know. I've not read anything like that about Ritalin. So although I'm apprehensive about it because it's a drug, I think it's on the same order as what kids use speed for, and so on, because they warned me about it at the drugstore.

Us: What did the pharmacist tell you about it?

Parent: He told me I had a month's supply the way the doctor had prescribed it and to keep a close check on it. "Do I have teenagers in the house?" "Yes." "Do you just stick this medicine in your cupboard?" "Yes." "Do you understand that this is what teenagers use as speed and you are responsible for this as a drug?" "If they find it in your cupboard and take it they can have their trip. You won't have your medicine." I don't have that problem. I never have had.

Comments such as the one from the pharmacist are joined with other comments and reactions from relatives. These comments and reactions, while in some instances well-intended, may exacerbate the problem by generating feelings of inadequacy, guilt, and hostility.

Us: Do you get any criticisms from persons that you are close to?

Parent: Yeah, my brother is a high school counselor. ...He deals with all kinds of kids from all ranges of finances, drug problems, beer problems, he's really down on the fact that I have David on drugs. He brought me a few articles on vitamin deficiency supposedly causing but until you can get a doctor to look into that angle of it, you know, what can you do for yourself? My mother says, "Well, I know you hear good and bad, but it is helping, he is improving, so until something better comes along this is a start." She's a very quiet, patient person and she's very sickly and cannot help me and has had rheumatoid arthritis from head to toe for 17 years. On a good day, like yesterday afternoon, she said: "You go to the store and leave David here." The thing that amazes most people--amazes me at the same time and gripes the living hell out of me is when David's with my mother for that hour yesterday you could not ask for a kid to be any damn better. He's so good he stinks. I walk in the damn door and that kid is all over the lights and the walls and the house and "I want a drink, I want a candy bar..." You know, Jesus Christ, you think you're gonna go crazy. I mean, that's just how I feel. I can't help it. Then, they stand there, you know, and say I don't know what's the matter with him. They look at me like I'm the green machine, you know, what the hell you walk in the door and the kid turns blue, you know! I have this really rotten influence on him is the impression they give me and...I think maybe, well not so much lately, but for a while I had this feeling that I oughta just pick up my keys and walk the hell out of the door and leave him the whole shittin' mess. Maybe after 24 goddam hours they'd know what the hell I'm talking about.

The picture that emerges as this parent presents her life experiences with her hyperactive child is not one of an uncaring, irresponsible parent. Rather, we see a confused, anxious woman who is confronted with a problem that she can not handle. She has experienced the early childhood of her two other children but David has presented a unique and complex problem. Even though she considers stimulant medication as something of a miracle drug, she is ambivalent about its use. She does not embrace it with enthusiasm. She expresses the wish that it need not be given and she entertains thoughts that, in spite of the consequences that she knows all too well, she might want to stop the medication.

Discussions with parents of other hyperactive children provide a striking contrast to the articles in the mass media, and in some, more scholarly, literature. In these articles parents, teachers, and physicians are excoriated for their invention of a "disease" (hyperactivity) and their use of shoddy "cures" for it. The titles of these articles suggest their posture: "The Myth of the Hyperactive Child," "Towards a Nation of Sedated Children," "Too Many Pupils are on Medicine," "Controlling the Mind Controllers," "Pills for Classroom Peace," "A Slavish Reliance on Drugs: Are We Pushers for Our Own Children?," "Classroom Pushers," "Chaining Children With Chemicals," "You May Not Know It, But Your Schools Are Probably into the Potentially Dangerous Business of Teaching with Drugs," "Drugging and Schooling" (Bruck, 1976; Conrad, 1975; Charles, 1971; Clement, Solursh & VanAst, 1970; Hills, 1977; Hambrick, 1974a; Hambrick, 1974b; Divoky, 1973; Swazey, 1976; Offir, 1974; Murray, 1973; Ladd, 1970; Krach, 1966; Vondehaar, 1975; Vinnedge, 1971; "Classroom Pushers," 1973; Witter, 1971; Whalen & Hanker, 1977; Wells, 1973; Welsch, 1974; Weithorn & Ross, 1976).

We do not dismiss all of the concerns raised in this body of literature. The abuses and dangers described by writers in this literature deserve consideration. While the lurid muck-racking in some of the books and articles does not serve the cause of reasoned analysis, danger of abuse or misuse of psychopharmacological technology is not to be dismissed lightly.

The medical literature is less vivid in tone and more tentative in content than the popular literature. However, the knowledge we might wish to have is not always available when decisions are to be made. In the 43 years since Bradley (1937) found that Benzedrine was beneficial in altering the hyperactive behavior of children, there have been many researches addressing the medical, neurophysiological, and psychopharmacological questions which surround the nature of hyperactivity and its treatment through psychoactive medication and other treatment modalities (Silver, 1971; Millichap, 1968; Sprague et al., 1970; Conners & Eisenberg, 1963; Eisenberg, 1971; Krager & Safer, 1974; Sprague, 1977). Several excellent recent summaries of these works exist: Interagency Collaborative Group on Hyperkinesis, 1975; Juliano, 1974; Arnold, 1976; Whalen & Henker, 1976; and Whalen & Henker, 1980).

One of the persistent issues in the literature concerns the definition and use of the terms "hyperkinesis," "hyperactivity," and the "hyperactive child syndrome." A considerable volume of literature has developed in an attempt to define and describe these terms. There has been extensive debate about the nature and etiology of this condition (see Interagency Collaborative Group on Hyperkinesis, 1975; Juliano, 1974; Arnold, 1976; Whalen & Henker, 1976; Bosco & Robin, 1977; and Whalen & Henker, 1980, for useful reviews and discussions). Not only have alternative conceptions been proposed, but the same term has been used in

different ways. Hyperkinesis, for example, is used by some to indicate a complex of behaviors including overactivity, distractibility, impulsiveness, and perceptual malfunction. Others have used the term in ways which suggest that hyperkinesis is identical with overactivity. Because of this confusion, some individuals in the field have raised questions about the legitimacy or utility of the terms "hyperkinesis" or the "hyperactive child syndrome." There is, however, substantial agreement among medical authorities that, though the variety of terms reflect an imperfect understanding of the condition, the terms do refer to a concrete medical entity.

Recently, DSM III, 1980, (Diagnostic and Statistical Manual, published by the American Psychiatric Association) provided a new diagnostic schema for hyperactivity. Under the general group heading "Attention Deficit Disorders of Childhood," a category called "Attention Deficit Disorders with Hyperactivity" is included. One of the major changes in the new orientation to diagnosis is the distinction between hyperactivity and conduct problems. Children with anti-social or aggressive patterns are not included in the DSM III Diagnostic category pertaining to hyperactivity.

The medical literature (Gittelman-Klein, Spitzer & Cantwell, 1978; Schuckit, et al., 1978; Oettinger, 1971; and Eisenberg, 1972) generally has stressed the need for careful diagnostic procedures involving physical, neurological, and psychological factors (e.g., intelligence and achievement tests, visual and auditory perception tests, motor coordination, laboratory tests such as liver function, kidney function, and integrity of blood-forming organs, tactile perception, and electroencephalograms).

Drug treatment is only one of a variety of possible treatments for the hyperkinetic syndrome. The literature contains information about other possible approaches (Eisenberg, 1971; Keogh, 1971; and Whalen & Henker, 1980. The decision to use a stimulant drug to treat a hyperactive child requires the physician to weigh the possible benefits of drug treatment against possible risk. In determining risk and benefit, it is necessary to assess the use of stimulant drug treatment relative to other approaches.

Much of the controversy has centered on the use of medication for treating hyperactivity. An excellent scholarly review of the questions involved in the use of stimulant medication is to be found in a new volume by Whalen and Henker (1980). In their lead article, they cite research findings which are often conflicting or inconclusive.

The essence of the concern for all of those who are involved in the care of hyperactive children is the question: Is

the use of the diagnostic term hyperactivity and its treatment with stimulants harmful or beneficial? While some may feel able to answer this question categorically, most recognize its profound complexity. Further medical and pharmacological research on the etiology and nature of the pathology and the efficiency and toxicity of drugs also may be helpful in resolving some of the issues.

There is, however, another set of important questions which, though suggested in the medical and educational literature have just begun to be approached more directly (Knobel, 1962; Freeman, 1966; Epstein, 1968; Cauffman, Warburton & Schultz, 1969; Arnold, 1971; Laufer, 1971; Weiss, Winde, Werry, Douglas & Nemeth, 1971; Eisenberg, 1972; Harlin, 1972; Glennon & Nason, 1974; Cole, 1975; Robin & Bosco, 1976). These questions focus directly upon the social context of hyperactivity and its treatment for school-age children: What do teachers perceive as their role relative to hyperactive children? Do they push psychoactive medication by badgering parents? What are the attitudes of parents and teachers about medication and other treatment regimens for hyperactivity? What patterns of relationship exist among physicians, teachers, and parents when a child is diagnosed or identified as hyperactive? Does the condition of hyperactivity and the way in which it is treated affect the way in which hyperactive children feel about themselves? Questions such as these exemplify an area of inquiry just now being approached.

The Interagency Collaborative Group on Hyperkinesis (1975) stated:

It would be difficult to overemphasize the importance of the social environment in discussing the etiology of behavior syndromes of children...Even the social behavioral view of hyperkinetic behavior is undoubtedly incomplete, some awareness of the social factors is necessary in considering the etiology and making treatment plans for the hyperkinetic child. (page 64)

Eisenberg (1971) underscored the importance of the social context of the child in the treatment program:

Effective treatment no more than begins with medication, remedial education and parent counseling are essential if teacher and parent are to help the child resume a normal development course. How rapidly he will progress is a function of the severity of his perceptual handicaps and family problems on the one hand, and of the adequacy of educational assistance and family therapy on the other. (page 711)

Loney (1975) noted that medication is demonstratively more effective in reducing the symptoms of hyperactivity with "well managed" hyperactive boys. She indicates by this that the family environment makes a difference in the success of medication. Thus, both the etiology and treatment of hyperactivity seem to be bound with the social context. We have (Robin & Bosco, 1976) argued that the broader cultural environment (i.e., the relationship among the larger social systems constituting the child's context, particularly educational, medical, and familial) provides a context which may be pervasive in its influence upon the course of the child's condition and treatment.

As we approached the controversy surrounding hyperactivity, therefore, it became clear to us that it would be useful to examine the social context in which the individual experiences of hyperactive children and their families occurred, and in which the controversy about hyperactivity and its treatment is generated and expressed. It appeared to us that the uncertainties about etiology, diagnosis, and treatment were being transliterated into statements of ideology, which in turn were then being reflected in the individual attitudes and behaviors of those involved and of commentators upon the scene. Since the social variables were seen as significant in the treatment of children who manifest the hyperkinetic syndrome, and since the factors and the controversy about the use of stimulant drugs seemed to entail social variables, it seemed to us that there was a need to investigate these issues within a framework which would be comprehensive enough to include the social context and the individual experiences of hyperactive children. The fundamental premise upon which proceeded as we approached the research task, therefore, is that the use of stimulant drugs for the treatment of children who exhibit the hyperkinetic syndrome is a social as well as a medical act. The purpose of our investigation, therefore, was to provide an understanding about the social process, and the controversy about that process of treating children with stimulant drugs for the symptoms of the hyperkinetic syndrome.

Our discussions with parents, such as the one we quoted at the beginning of the chapter, tended to reduce our willingness to take a doctrinaire stance. We have sought to understand the world of the hyperactive child and the perspectives of those who intersect with him in significant ways.

In the four years since we spoke with the first parent quoted in this chapter we have examined several thousand questionnaires and over 600 interviews with parents, teachers and physicians. The social reality of hyperactivity is clearer to us now than it was then. In the pages that follow, we will describe how we evolved concepts and processes to study the social process, and what we now understand.

CHAPTER TWO

EVOLVING AN APPROACH

In 1973 both principal investigators were administrators in the Grand Rapids Public Schools - Western Michigan University Center for Educational Studies. Our responsibility with the Center involved the designation of areas for educational research that could be pursued through the Center. In the early 70's, more and more was being said and written about the abuses of medication in treatment of hyperactive children. We had heard and read in newspapers, magazines and television about some of the controversies concerning the use of medication. Our discussion with Grand Rapids School System administrators led us to recognize the need for a study to ascertain if the problems described elsewhere were present in Grand Rapids.

We developed a study to investigate Grand Rapids teachers' perspectives on the use of Ritalin for hyperactive children. A mailed questionnaire was sent to a 20% sample of elementary school teachers in the Grand Rapids Public School system. The questionnaire contained three sub-sections. The first section contained questions concerning the teachers' views about the appropriateness of using Ritalin for hyperactive children. The second section dealt with teacher information about attitudes and knowledge pertaining to Ritalin, and the third section concerned the teachers' perception of their professional role with regard to the use of Ritalin.

We found a considerable volume of literature dealing with efficacy and toxicity of drug treatment; we found a number of papers presenting opinions about how physicians, teachers, and others involved in treatment programs should function; there were articles dealing with the evils of the use of medications for hyperactive children, but we could find no other research studies wherein teachers' beliefs or behaviors were actually investigated. This seemed to us to be an unfortunate oversight in the literature. Since so much of the controversy and problems with the use of stimulant medication hinged on questions pertaining to the ways in which teachers functioned, their interactions with parents and physicians, we saw a need for empirical study of these questions in the literature.

In our study (Robin & Bosco, 1973), we found that the attitude of teachers toward the use of Ritalin was cautiously favorable. We found about one-third of the teachers felt that Ritalin had resulted in major improvement in the lives of hyperactive children, that about 40% felt Ritalin had limited use and about 13% were critical of Ritalin (16% did not respond). We also found that teachers did not have much information about the characteristics of the drug. On a series of simple, straightforward factual questions the modal response was "don't know."

The most important finding for us was the extent of confusion reflected by the teachers about the teacher's role in a Ritalin regimen. The response to a series of questions about what teachers should do showed a pronounced lack of consensus. We did not find as much pro-medication attitude among teachers in our sample as the exposé led us to expect. Also, we were concerned about the lack of information at the teachers' command and their uncertainties about their professional behaviors.

These concerns led to a second, expanded study (Bosco & Robin, 1976) which contained several aspects. One aspect was a replication of our initial study. A second entailed an examination of prospective teachers' attitudes, beliefs, and teacher role expectations with regard to hyperactive children. A third part involved an analysis of instruction about hyperactivity and its treatment in undergraduate teacher education classes. A fourth section was content analysis of textbook materials about hyperactivity and its treatment in relevant education courses.

These investigations told us several things. First, the replication of the study of teachers in Grand Rapids (again done with a 20% random sampling of elementary K-8 classroom teachers) provided very similar findings to those of our first study. There were no major differences between the results of the two studies.

Further, we found that prospective teachers (education majors at Western Michigan University) received little information about Ritalin or the policy problems which accompany stimulant drug usage. Our examination of attitudes toward Ritalin and role expectations, spanning the years between freshman and sophomore college class levels to 12 or more years of teaching experience, showed us that there was generally a similar conception of role over time. Experienced teachers held attitudes similar to the less experienced teachers. There was, however, an increase in positive attitude toward Ritalin use for hyperactive children between college years and the first few years of teaching.

We found that the information which was presented to prospective teachers in education classes was generally unsystematic and spontaneous. Information was likely to be the result of questions presented to instructors.

Our content analysis of textbooks in education resulted in no content to analyze. An examination of thirty-six education courses with content closest to the problem of the hyperactive child produced no relevant content. The textbooks simply did not present information about hyperactivity.

These studies led to several major conclusions. The first was that the issues we were exploring were serious and deserving of careful, thorough and comprehensive investigations. While it

seemed likely (although far from clear) that the hyperactive children constituted a relatively small portion of the student population in the school district, the welfare of these children required better information about problems of teachers and others having the responsibility to care for them. Also, it seemed that, although many of the issues in the controversy reflected different philosophic and ideological viewpoints, some of the contentions, which were grist for the polemic mill, were matters which could be subjected to empirical examination. Why, for example, was it necessary to speculate about the number of children being diagnosed as hyperactive children when we could go out and count the number? Why was it necessary to speculate about the magnitude of the stereotyping or stigmatizing of children when it would be possible to see how often and in what ways such behaviors occurred?

We also recognized several limitations in the work we had done. Our previous work had relied almost exclusively on questionnaires which limited the kinds and extent of information we could obtain. We had only collected data from one key participant in the process - teachers. We had asked teachers about their interactions with parents and physicians. They had reported the situation as they perceived it (very limited contact). Yet, we came to realize it would be necessary to get information from the other key participants themselves rather than to merely use the reports of teachers as the basis for understanding the situation. We had not involved the most important key participant in our research: the child. While everyone spoke about the child, no one spoke to him. Our studies had been confined to one stimulant drug: Ritalin. We had done this because it seemed to us that Ritalin was the most familiar and most recognizable aspect of the problem. We did not want to confuse our respondents by referring to psychoactive or stimulant drugs. However, we were not concerned with a particular product but rather a kind of treatment and thus we realized that our previous studies which had focused on Ritalin needed to be expanded.

There was one additional, even more fundamental, limitation. This was the limitation of our perspective. Our first studies were conceived of as social research on the repercussions of a medical act - the diagnosis and treatment of hyperactivity. As we examined our data and learned more about hyperactivity and its treatment, we realized the usefulness of considering it as a social act. An analysis of the problems connected with diagnosis and treatment shows that many of them entail the ways persons function and interact. This is evident as we consider some of the contentions about the problem:

1. Normal behavior is defined by parents and teachers as pathological.

2. Physicians do not diagnose properly. They fail to analyze the situation adequately.
3. Teachers and physicians fail to communicate when diagnoses have been made; information about the child's behavior in school enters into consideration in a vague and incomplete manner.
4. The persons who have diverse but important information about the success of treatment do not interact cohesively.
5. Medication is used because more useful but complicated approaches are avoided.
6. Children who are treated with medication are subject to stigmatization and stereotyping.
7. Teachers are overly assertive in suggesting medication.
8. Parents feel guilty about the behavior of their child and this guilt compounds the problem.

Inspection of these programs shows that the determination of the validity of these statements and an explanation of why they are so (if they are so) requires more than is provided by medical or pharmacological information. The recognition of a need for treatment and the assessment of the success of treatment often involves teachers. As a dependent, not completely responsible member of society, the child's status as a patient is mediated by his parents. The child is not the ultimate decision maker; he cannot seek, accept, or reject medical treatment. The relationships of the child to his parents and to the family are important factors in the treatment of hyperactivity. The prescription of medication falls within the realm of physicians; the decision to solicit medical treatment and use prescribed medication lies with the parents. Therefore, since we are dealing with children for whom the treatment of hyperactivity is frequently school-connected, the prescription and use of stimulant drugs is a social act involving at the very least parents, teachers, and physicians.

While there are alternative ways to explain the functioning of these three critical participants, as we thought about our preliminary studies and the information in the literature it seemed to us that social systems theory provides a substantial basis for analysis. By using social systems theory we have a way of analyzing and understanding the behaviors of these persons in terms of their functions within their social settings. When we thought about the problems, we tended to see the transaction and interaction as doctor with parent not as Dr. Schwartz with Mrs. Smith.

What was required was an understanding of how the people who make and implement the important decisions relative to these questions about hyperactivity function and interact. We saw the need for an approach that was not confined to the medical domain but included it in a broader social perspective which needed to be articulated and elaborated as a basis for empirical research and policy for the treatment of hyperactivity.

When we focus on parent, teacher, and physician functioning in their social systems, we are using an orientation for which the construct of role is quite useful. In the role literature, alternative conceptions of role have been formulated. Role has been used prescriptively, descriptively, and evaluatively in relation to the behaviors of individuals (Gross, 1957; Biddle & Thomas, 1966; Parsons, 1942; Robin, 1964; and Jackson, 1972). As Biddle and Thomas indicate, however, role has most typically been used by role theorists to mean the set of prescriptions which defines a person's behavior. While norms do not predict actual behaviors with certainty, norms, or expected behaviors, constitute a most important social phenomenon. While individuals in a social system can--and do--function non-normatively, norms provide the essential structuring of regular, predictable patterns of behavior on the part of persons in the systems. Sets of norms comprise roles. The usefulness of role as an explanation construct is expanded when it is tied to a social systems theory.

The treatment of children with stimulant drugs involves the medical, educational, and familial social systems. Social systems is a construct which is used to provide a unifying structure to social elements which are functionally related. These elements are bound together in a specific fashion which, as described by Williams (1960), has a "...definite arrangement of parts having boundaries, unity or cohesion, resistance to external forces and enduring through time..." The orientation to social systems in this discussion is strongly influenced by Kuhn (1974) and Monane (1967). Kuhn's and Monane's works are elaborations on earlier theoretical positions articulated by Parsons (1951, 1961), Homans (1950, 1961) and Loomis & Loomis (1961).

As discussed by Monane, social systems are characterized by cultures or ethos. Specialized knowledge in some areas, the absence of knowledge in others, and particular beliefs and attitudes are found on the part of those socialized to the roles in social systems. The cultural content of social systems varies with the function of the social systems. Persons occupying positions in one social system may have knowledge which persons in another system do not have. Persons in one system may have attitudes and beliefs that differ systematically from those in other systems, or they may have attitudes and beliefs about matters unknown to those in other systems.

Social Systems Structure and Functioning

The medical, familial, and educational systems have quite different structures. The structures differ with regard to process and goals. The medical system is marked by an interaction with children which is of short duration (time per interaction) but of long continuity. The system exercises relatively great control over children. Its goals, the prevention and cure of illness, are clear and constitute relatively precise criteria for appropriate behavior differentiated and steep (great social distance between members of the system). The educational system has interaction with the child of long duration but of short continuity for any given individual within the system. This system has limited and highly prescribed control over the child. Its goals, education and selective socialization of the young, are more ambiguous than those of the medical system. This system has a high differentiation (though less than the medical system) and moderate steepness. The familial system has interaction with the child of longest duration and continuity. This system has greatest (of the three systems) control over the child. Its goals in regard to the child are multiple, vague, and sometimes conflicting. The social structure has some differentiation but relatively little steepness.

The structure of each social system influences its members' perceptions of the child. Since the structures of the three systems are quite different, the definition of the child and his problem varies from system to system. Thus, in one sense, members of each system see a different child with a different problem. Since the three systems are quite different, the definition of the illness and the technology used to treat it vary from system to system.

Effective diagnosis and treatment require that members of a particular social system modify existing roles or develop new roles in order to relate to members of other social systems. Thus, the teacher may need to work with the physician as an important participant in the evaluation and assessment of the medical treatment. These roles which entail complimentary behaviors on the part of members of different social societies are called "reciprocal roles." Reciprocal roles are roles in which the expectation for behavior interface with parallel roles in another social system. The reciprocal roles comprise the "glue" that bind social systems together to accomplish tasks not confined to a single social system and requiring the articulation of more than one social system. If the social structures are markedly different, the development of these reciprocal roles is difficult and the probability of systems interaction decreases.

The roles within a system reflect the structure, functioning, and goals of that system. The greater the dissimilarity of social systems, the greater the differences in the norms that comprise the roles that must be reciprocal in order for the social systems to articulate. Put less arcanelly, there must be some similarity in the things people expect to do, in the things they do and in their general perspective before they can be expected to act jointly in a complicated task. If their social systems are quite different the systematic convergence of behaviors is quite unlikely. If the social systems are quite different the creation of reciprocal roles may be impossible.

In order to achieve intersystem articulation for tasks for which no reciprocal roles now exist, existing roles must be modified or new roles created. Systems, however, are not alike in their propensity to invent or modify roles. The ability to develop intersystem articulation by creating reciprocal roles is governed by the least responsive system.

We have already noted that the internal structures of the systems involved in stimulant drug treatment are different. Therefore, the lack of interaction is predictable and the development of interaction is problematic. It is relatively easy for journal authors to view the treatment of individuals with stimulant medication in a holistic, nonparochial manner, but for a system member such a perspective is considerably more difficult to achieve. Even though the diagnosis and treatment may be considered to transcend the functions of any one system, it is viewed by system members from the perspective of the goals and the nature of their system. Therefore, the child's problem is segmented. Frequently, this segment, as defined by a single social system, comes to be redefined as the totality by the members of that system. The popular notion of a team approach, for example, in the treatment of hyperactivity implies a shared or common goal. Yet, for the child who is being treated for hyperactivity, there may be three somewhat different goals. In the medical system the task of treating the hyperactive child is viewed from the perspective of the goal of the prevention and cure of illness. In the educational system, this task is viewed from the perspective of the education and socialization of the young. This drug technology, therefore, is viewed from very different perspectives and comes to mean something different to the members of each social system although objectively it is the same technology impacting upon each of the social systems.

In order to use a technology such as stimulant medication which requires the collaboration of more than one social system, a series of social inventions may be required. These social inventions are the reciprocal roles which should be crafted so that the behaviors expected are simultaneously appropriate for the social system in which the role resides, coherent with regard to the other social system(s) with which it is reciprocal, and

relevant in content to the task at hand. This is not easy to achieve with decidedly different social systems. There are, in addition, some systematic barriers to social system articulation.

The Permeability of System Boundaries

Social systems, by definition, are bounded. The boundaries of systems mark which persons, communications, and cultural items such as norms and technology are internal and which are external. Boundaries are inhibitors of system contact and change. The permeability of boundaries or openness of the systems which deal with hyperactive children are markedly different. The medical social system is comprised of highly credentialed individuals and those seeking medical help. Patterns of communication are highly prescribed and communications from outside the system do not find ready admission and acceptance. It is a strongly bounded system. The educational system is less strongly bounded. Entrance as a professional is less demanding. The family is the most open system. Membership for most is automatic at birth and the vast majority of adults marry. Communication and other cultural elements find relatively ready admittance. The variation in openness is directly related to the ability and proclivity of systems to develop roles which are reciprocal to roles in other systems. Moreover, the openness of systems affects the flexibility of role relationships in accomodating contact with other systems so that interaction is also affected. For treatment of hyperactivity, permeability of the medical system is difficult, frustrating, and controversy-producing for members of the other systems. The educational system presents a similar, if less acute, problem.

Change in Social Systems

While it is widely asserted that social system interaction is requisite to effective application of stimulant technology, our analysis leads us to recognize that the interaction of systems is likely to be imperfect at best. In order for interaction to occur, change in social systems is required.

The multiple system membership of hyperactive children, the educational bases of stimulant drug prescription and the overall responsibility of parents for their children's health and education indicate that stimulant drug treatment is a social process shared by the medical, educational, and familial social systems. This implies the need for social systems interaction. Some interaction of systems almost always exists in the case of children on stimulant drugs. Parents are called to school or receive reports on the educational progress of their children. Parents take their children to physicians who are empowered to prescribe medication. But, this does not constitute the

coherent articulation of social systems required for an effective application of stimulant drug technology.

As the number of systems that are directly involved with the application of a technology increases, the problems in applying the technology also increase. As a corollary to this, successful application of this technology is limited by the most resistant system. The requirement for system collaboration for the application of technology imposes changes which go beyond those which stem directly from the technology. Thus, if we are to speculate about the future of psychopharmacological technology, we must recognize that it requires both changes within several social systems and changes in the relationships of systems one to another.

Failure to respond to the social system change demands of the technology does not necessarily result in a complete rejection of the technology. In a partial and imperfect application of the technology, the potential of the technology might not be realized. The possibilities of controversy increase. Consequently, it is difficult to know whether problems with the technology stem from the technical quality of the technology or its imperfect application in a social system. There is good evidence that this has been the case in the prescription of stimulants for hyperactive children (Robin & Bosco, 1973; Bosco & Robin, 1976, and Robin & Bosco, 1977).

Beliefs as Context

One of the important factors in the coherence of the hyperactive child's world is the convergence and similarity of beliefs about his condition and treatment held by the adults who control his life. Monane's observation that social systems have unique cultures or ethos, combined with our analyses of the differences among the medical, educational, and familial social system and the general resistance of social systems to change and develop reciprocal roles leads us to question whether the beliefs among parents, teachers, and doctors will not be quite different. When a set of beliefs is confined to a single system, such as surgical techniques, then shared beliefs predominate and disagreements are found primarily on the cutting edge of knowledge and beliefs. Even then their resolution is advanced by common domain assumptions.

The nature of the discourse about stimulant technology, however, ranges over all the questions of efficacy, need, and morality. Is it effective? Is it needed? Is it ethical? The locus of action for the technology is not confined to a single social system, the medical system, but involves other systems for its application. The implementing systems, with regard to the use of stimulants for the treatment of hyperactive children,

are the familial, medical, and educational systems. No one of these systems can determine the way in which or the extent to which this technology will be applied. If the technology requires the active participation of the members of several systems for full application, then the extent of divergence of beliefs among members of these systems becomes important.

Research Questions

The concepts of social system which we have presented in the section above served to focus our investigation of the diagnosis and treatment of hyperactive children. The salience of beliefs and attitudes and the important formulation of roles in the establishment of coherence among the three critical social systems leads to the following three questions:

1. What are the beliefs and attitudes of physicians, teachers, and parents concerning the hyperactive children?
2. How do teachers, parents, and physicians conceive of their roles of others relative to the hyperactive children in their care?
3. What are the modes of social systems interaction with regard to the treatment of hyperactive children?

In addition to these questions, there were three other questions we sought to answer:

1. What is the prevalence of diagnosed hyperactivity and the treatments for it?

Estimates for the number of children treated with stimulant drugs vary widely (Bosco & Robin, 1980). There is perhaps even less certainty about the number of children currently diagnosed as manifesting the hyperactive child syndrome. One logical and highly functional basis on which to begin constructing reliable estimates of prevalence of diagnosed hyperactivity and the approaches to treatment is by using the school system or district as the unit of analysis. One of the specific aims of this research was to provide detailed descriptive information concerning the proportion of the student population diagnosed as hyperactive, the distribution of diagnosed hyperactivity by variables such as sex, social class levels and age. Additionally, data were gathered to indicate other characteristics of the diagnosed children, such as SES and age of hyperactive children receiving no treatment, treatment with various stimulant drugs, other drug treatments, and other non-drug treatments such as operant conditioning, nutrition therapy, mega-vitamin therapy, counseling, etc. These data provide a demographic baseline against which other findings of this research can be compared.

The information about the prevalence of children treated with stimulant drugs can be used in order to extrapolate findings from other segments of the research. If, for example, it is learned that a particular outcome occurs with x number of children in the sample, the information about the prevalence of comparable children in the population (children in the Grand Rapids School System) can be used in order to determine the number of children in the total population who might be similarly affected.

2. What are the events and procedures for the diagnoses and treatment of hyperactive children?

The "natural history" of stimulant drugs treatment is unknown. It is also the basis of controversy. Medical personnel have accused teachers of "prescribing." Teachers have decried the uncritical prescribing of stimulant drugs for their students. Physicians and teachers have noted that parents, on the basis of casual information, have pushed for the prescription of stimulants or have resisted or subverted the regimen. As a matter of fact, however, the truth of the allegations, or their frequency are not addressed empirically in the literature. The lack of clarity about the events and procedures of diagnoses and treatment is grounded in the three system nature of the process. Evidence of difficulty in social system articulation may be seen in the differing prescriptions of how children are diagnosed and treated as perceived by parents, teachers and physicians.

3. How do hyperactive children perceive the experience of being diagnosed and treated?

At present, there is little information from the child's perspective about treatment with stimulant drugs. This question is salient to the treatment process for two reasons. First, the child is the object of the treatment. Even though the cause of hyperactivity is usually assumed to be physiological, the child's expectations about his ability to modify his behaviors may well influence the probability of such behavior modification occurring. Second, the child is the only common member of all three systems. As such, the child may be subject to stereotyping, stigmatizing, and a variety of responses from all three systems. The child may suffer the double burden of being viewed as "different" because of the behavior associated with the hyperkinetic syndrome and because of the stimulant drug treatment intended as a remedy.

Since the child is a member of three systems, and constitutes an irreducible point of contact, he may be in a position to influence (particularly the older child) the initiation, monitoring, and termination processes. The extent and nature of the child's knowledge is important to these processes. Ultimately the consequences of effective or faulty functioning and interaction of the parents, teachers, and physicians impinge on the treated child. To neglect to obtain the perspective of the child

would constitute a major gap in our understanding of the social context of the disorder and its treatment.

CHAPTER THREE

METHODS

The General Design of the Study

The research was conducted in the Grand Rapids, Michigan Public School system. Grand Rapids is the second largest city in Michigan and has a population of 200,000. At the time the data were gathered the public school system was comprised of 50 elementary schools, nine junior high/middle schools, and four high schools. It had a student population of 30,550 and employed a professional staff of 1,850.

In order to gather our data, it was necessary to develop a process for locating children who had been diagnosed by physicians as hyperactive. Once located, these children could be used as the basis to identify the teachers, parents, and physicians, each keyed to a particular hyperactive child. An important byproduct of this process was an estimate of the prevalence of diagnosed hyperactivity in the public school system and the frequency of use of alternative approaches.

In considering the hyperactive child's environment, it seemed useful to classify subjects into three distinct treatment phases: the initiation phase, which included hyperactive children who had recently been placed upon a medication regimen - all children who had been diagnosed during the 1976-1977 school year were considered as being in the initiation phase; the monitoring phase, which included children whose treatment predated the 1976-1977 school year and who were still being treated; and, the termination phase, which included hyperactive children who were no longer being treated with stimulants.

As we began collecting data, we established a fourth category. "type two termination" was comprised of children whose medication had been terminated for more than two years prior to the beginning of the 1977-1978 school year. These type two terminations were so designated because the data would need to be collected from that teacher in whose class the student was at the time of initiation. The type two termination subjects presented the double problem of retrospective data and the difficulty of determining and finding the appropriate teacher. Consequently, we did not interview teachers of type two termination subjects.

The major advantage that we perceived in designating the sample in phases was that this approach would enable us to minimize the necessity for retrospection on the part of subjects. We recognized that many of the questions we would be asking during the interview required fairly detailed information about what happened, when, by whom. By employing an approach which minimized the time lag between the events being recalled and the

interview, we hoped to insure the quality of the information. Also, dividing the interviews into phases enabled us to reduce the amount of time required for each interview by asking the respondent only those questions relevant to the appropriate phase.

When we began to draw the samples for the interviewing and noted the distribution among the phases, we had second thoughts about the desirability of the phase approach. (see Chapter 4)
 - In retrospect, we should have reduced the number of questions, selected among the questions we used in each phase, and gathered data about the total process from each subject interviewed.

In our sample of hyperactive children we found fewer children in the initiation phase and the monitoring phase than had been anticipated or desired. This led us to develop a second sample of hyperactive children from whom data, particularly of the initiation and monitoring phases, could be gathered. Accordingly, a sample of diagnosed hyperactive children from Kalamazoo, Michigan, was obtained from the "Live Y'ers" program begun in the summer of 1977. The program was intended to develop behavioral control for the children and was sponsored by Bronson Hospital, Kalamazoo, Michigan, and the Kalamazoo, Michigan, YMCA. Children admitted to this program were volunteered by their parents and were screened by the professional staff of the program; all were taking medication for hyperactivity. The children and their parents enrolled in this program were interviewed with an instrument that combined the characteristics of the mailed questionnaire sent to the Grand Rapids sample and the initiation and monitoring phases of the interview schedule used for the Grand Rapids sample.

Developing Instruments

We began our research by conducting a set of unstructured interviews with parents of hyperactive children. We developed a series of open-ended questions which dealt with the range of issues and problems that we intend to examine. (See Appendix A for the open-ended interview schedule.) We conducted four interviews of approximately two hours duration each. We used these interviews as one basis for generating items that could be used in the various subsections of the interviews. These interviews also gave us a sense of the appropriate language level. At the same time, we began an extensive analysis of the literature as a means of generating instruments and engaged in discussions with medical and educational consultants. As a result of our interviews, our review of the literature, and our discussion with consultants, the prototype instruments were developed. They were reviewed by a panel of experts and following these consultations we revised the mail questionnaire and the interview

schedules.*

In developing the instrumentation for the interviews, we recognized the complexity of the issues that we were addressing. We recognized the difficulty in interviewing teachers, parents, and physicians with the same schedules. We saw the need to avoid imposing a particular set of terms or frame of reference on those whom we would be interviewing. Also, the questions had to be understandable to the most naive parent or teacher and, at the same time, not appear simpleminded to the most sophisticated physician. We also recognized the need to isolate the central critical issues and problems in this very diffuse and ill-formed area.

Another problem was a consequence of the need to develop interview instruments which could be used by an interviewing staff. Given the number of interviews that were required for the conduct of the research, it was impossible for the principal investigators to conduct all of them. It became necessary to develop questions which would capture the important and complex issues involved in the social context of the hyperactive child's life in a way which enabled use by persons whom we would train.

We will describe the instruments developed and used with our case finding and prevalence stage and the five research questions. (Copies of all instruments used in the study are contained in Appendix A.)

Prevalence of Hyperactivity and Development of a Sample of Hyperactive Children.

Two instruments provided data for this stage of the research: a parent questionnaire and a teacher questionnaire.

Parent Questionnaire: This questionnaire was designed to be sent to parents and was constructed so that it would refer to a specific, designated child. The first section of the questionnaire elicited information about the general demographic characteristics of the family, namely, the ages and sex of children in the family, the ages of the parents and occupations of parents. The remainder of the questionnaire referred to a particular child. Since many families in our sample had more than one child attending the sample schools (or other Grand Rapids Schools), we had to find a

*These consultants were: Dr. Mitchell Balter, Chief, Special Studies Section, National Institute of Mental Health; Dr. Ronald Lipman, Chief, Clinical Studies Section, National Institute of Mental Health; Dr. Keith Connors, Professor of Psychiatry and Director of Research, Children's Hospital, Washington, D.C.; Dr. Donald Waterman, St. Mary's Hospital, Grand Rapids, Michigan; and, Dr. Edward Birch, Assistant Superintendent for Special Education, Grand Rapids Public School System.

way to orient the respondent to the child in question. We did this by placing a computer-produced name label for each child in the sample on the questionnaire with the instruction that the questions asked all pertained to that child.

The most difficult problem faced in designing this questionnaire was that multiple terms are used as diagnostic terms for children who comprised our sample. Also, we wanted to sort out children whose diagnosis as hyperactive had been made by a psychologist, social worker, or the like, rather than by a physician.

We used a three-tiered approach. The first question asked was open-ended: "Has your child had a medical diagnosis of a learning or behavior problem?" If the response was yes, we asked the parent to indicate what the diagnosis was and who had made it. The following question was closed-ended and listed eleven of the terms which are used synonymously by some as diagnostic terms for the hyperactive child syndrome. The questionnaire was designed so that the respondent had to turn the page to encounter it, after responding to the prior open-ended question about diagnosis. The third tier consisted of a request for the parent to look at the label of the child's medication and indicate the name of the medication. By examining these three questions in juxtaposition we were able to derive information (which could be internally validated) for the purpose of weeding out children who either had not been medically diagnosed or had been medically diagnosed for some condition other than hyperactivity.

The second section of the questionnaire consisted of a list of the common treatments for the hyperactive child syndrome. It asked parents to indicate which treatments had been used and when they had been started and ended.

The third section of the questionnaire consisted of the "Conners Parent Short Form." This is a frequently used screening instrument used to determine if the child's behavior is perceived by the parent as non-normative on ten of the symptoms associated with hyperactivity.

This instrument was used to gather information for measuring prevalence and was also employed to locate the sample of hyperactive children who would be used in addressing the other research questions.

Teacher Questionnaire: The teacher questionnaire was designed to elicit data from the teacher for cross-validation of the prevalence information we received from parents. The teacher questionnaire paralleled the parent questionnaire except that ethical concerns constrained us from requesting information from the teacher which would have identified children by name. The teachers were first asked to indicate how many children they believed exhibited the symptoms of the hyperkinetic or hyperactive

child behavior pattern, and how many children in their classes had been diagnosed by a physician with any of the eleven diagnostic terms that we had used in the parent questionnaire. This juxtaposition allowed the teacher to exercise her own judgment as to the presence or absence of hyperactivity as distinct from her knowledge of the physician's diagnosis. We were concerned that the teacher not confound her knowledge of the diagnosis with her knowledge of the children and provide us, thereby, with separate information about each.

The second part of the questionnaire dealt with the treatment of children. Again, it paralleled the parent questionnaire but used the class as the unit rather than being child specific. We asked the teacher to tell us the number of children in her class being treated with mega-vitamin therapy, counseling, special diet, remedial instruction, behavior modification, psychiatric treatment or medication for behavioral or learning problems. We were aware that these treatments could well be used for hyperactive children but the number of children specified would not be confined to hyperactive children.

Events and Procedures for the Diagnosis and Treatment of Hyperactive Children.

To investigate this question instruments were developed to provide a description of the sequence of events and the behaviors of parents, teachers, and physicians who were associated with the diagnosis and treatment of children. We developed nine instruments - one for each combination of sample and phase of child's treatment (parent initiation, parent monitoring, parent termination, teacher initiation, teacher monitoring, teacher termination, physician initiation, physician monitoring, physician termination). We developed two additional instruments. One was for children who had been diagnosed but were untreated, and the other for the Kalamazoo parents (the Kalamazoo interview combined the initiation and monitoring phases).

The interviews were constructed to have probes to follow certain lead questions. For example, when inquiring about the kinds of adjunctive therapies that were used in addition to medication treatment, if the respondent indicated that some adjunctive therapy was used, the instrument provided a series of specific adjunctive therapies for the respondent to specify.

The instruments that were used for parents, teachers, and physicians in the initiation phase contained the following sections: problem recognition and response, diagnosis, medication treatment and adjunctive therapy, attitudinal contexts, and psychological and social support. The monitoring instruments contained one section on monitoring, a section on social and psychological context, attitudinal context, adjunctive therapy, and medication treatment. The interview schedule for termination contained a section on termination, social and psychological context, attitudinal context, adjunctive therapy, and medical treatment.

The interview schedules for parents, teachers and physicians, while tailored to their own unique possibilities for participation in the child's regimen, remained as parallel in form and content as possible. The instruments for untreated children consisted of sections on attitudinal context, social and psychological support.

The Beliefs and Attitudes of Physicians, Teachers, and Parents Toward the Hyperactive Children in Their Care.

Assessment of Treatment, Parents, Teachers, and Physicians: This instrument was divided into three sections. The first section dealt with the seriousness of the child's problem prior to the initiation of medication treatment. Respondents were asked to indicate the seriousness of the problem on a seven-point scale ranging from "normal-no-problem" to "almost intolerable to live with" for parents; "among the most serious problems I have seen in my patients" for physicians; and, "among one of the most serious problems I have seen in my students" for teachers.

The second section of this instrument dealt with the change in the child's condition since the medication treatment began. This was on a seven-point continuum ranging from "very much improved" to "very much worse."

The third section of this instrument dealt with side effects and elicited information about the existence of side effects and, for those who reported side effects, the description of observed the side effects. There was also a section in which the respondent rated the seriousness of side effects on a five-point continuum ranging from "barely noticeable" to "severe requiring discontinuation of medication." These instruments were developed using as a basis (MH9-28173 Clinical & Global Impressions, 1973).

General Attitude Toward the Use of Medication for Hyperactivity: An eight-item Guttman scale was developed to measure the respondents' feelings about the use of medication for the treatment of hyperactivity. The items in this scale were developed from polemic statements found in the mass media and some points of view developed in the more scholarly literature. Prior versions of this scale were used in our research about the attitudes of teachers (Robin & Bosco, 1976; Bosco & Robin, 1977). (The procedures and details of the Guttman scaling are found in Appendix B.)

Specific Attitudes Toward the Use of Medication for Hyperactive Children: This instrument consisted of three items which elicited information about the attitude toward the use of medication for the child in the care of the respondent. It described a positive to negative continuum (from no reservation about the use of medication for the child through ambivalence to disfavoring the use of medication for the child in question).

Beliefs about Hyperactivity and Stimulant Drug Treatment:

This instrument was developed to identify parent, teacher, and physicians' beliefs about hyperactivity and stimulant drug treatment. It contained several sections. The first section requested information from the respondent about their views on the nature of hyperactivity. We also asked about their beliefs about the causes of hyperactivity. These items were open-ended. The second section consisted of ten items which presented alternate beliefs about the etiology of hyperactivity. The instrument brought before the respondent the major positions expressed in the literature about factors which are posited as possible causes of hyperactivity; the respondent was asked to indicate agreement or disagreement or uncertainty about each of them. A third section contained information about the consequences of medication treatment. We asked subjects about the typical length of medication regimens, the side effects of medication, the criticisms of the use of medication, and the response to the criticisms of the use of medication for hyperactive children. The final section in this instrument consisted of five items which dealt with factual information about medication, i.e., medication as a stimulant, medication as a tranquilizer, and so on.

The physician instrument was parallel to the parent and teacher instrument but it requested additional information about the proclivities of the physician in employing various terms in diagnosing hyperactivity. In addition, it modified some of the questions about the nature, ideology, and consequences of hyperactivity to make them more appropriate for the physician.

The Perceptions of Hyperactive Children About Being Diagnosed and Treated.

For this question we developed an open-ended interview schedule. In interviewing children we recognized the diverse ages and experience levels of the subjects who would be asked to respond. We felt that the only way to deal effectively with this variability was to create a flexible instrument for use by sensitive interviewers. The instrument contained lead questions which were followed by alternate probes depending on the response to the lead questions. We also provided alternative forms of the lead questions so interviewers had options for restating the question if not understood by the child. The interview schedule was organized so that the interviewer could terminate the interview at various stages if the child's comprehension of the subject matter was simply not appropriate to the questions being asked.

The interview dealt with the child's awareness of his or her condition and the treatment of it, their experiences as a "hyperactive child" with parents, teachers, physicians and their peers, and the logistics of medication treatment, i.e., where, when, and how they received medication, their attitudes toward treatment, and their beliefs about treatment.

The Perceptions of Teachers, Parents and Physicians about Their Roles and the Role of Others Toward the Hyperactive Children. The Patterns of System Members Interaction with Regard to the Care of Hyperactive Children.

Data for the examination of both of these questions were gathered through a 35 item role inventory. This inventory was developed by analyzing the sequence of events for the hyperactive child ranging from the recognition of a problem to the termination of treatment. We wanted to provide items, for the role inventory, which were indicative of the activities of physicians, teachers, and parents at all stages of the process. Further, we attempted to exclude from this instrument items which would constitute unusual and esoteric behaviors. The item pool was developed from the unstructured interviews, the literature search, and the discussions with our consultants. The role inventory instrument was intended for the interviewee response in the abstract. What should be done for hyperactive children in general. Therefore, for the theoretical purposes involved, all respondents irrespective of sample or phase responded to the same instrument.

Internally, the instrument had several dimensions. We first asked the respondents whether they thought the behavior specified should be engaged in. This we labeled the inclusion dimension. If the respondent answered affirmatively, we asked who should be and who should not be involved relative to this behavior. This we labeled legitimacy. Finally, we asked the respondent to indicate who has the main responsibility for the initiation or execution of the behavior. This we labeled dominance. The role instrument, therefore, yielded three measures for each individual.

Preparations for Data Collection: Instrument Refinement, Pretests and Interviewer Selection and Training.

In order to refine the instruments we conducted a pre-test using all instruments and procedures developed for the study. We secured permission to mail questionnaires and conduct interviews in the Kalamazoo school system. Two schools were selected by school administrators.

One of the first procedures to be tested was the selection and training of interviewers. The competence of our interviewing staff was critical to the success of the project. Extreme care was exercised in interviewer selection.

We had several criteria for interviewer selection. The first was the requirement that the interviewers be female. Since most of the parents interviewed would be mothers, we felt the

need to maintain rapport, we sought to eliminate the social strain of male interviewing female, in the interviewees' home, about issues involving quite intense feelings. The second criterion was that the interviewers be mature. We knew it would be necessary to have interviewers who had the capacity to deal with very difficult situations without regard to their own biases and beliefs. We sought interviewers who had background in education since we believed that such persons would more likely have information and skills which would make them more likely to have or achieve the skills needed in the interviewing situations with parents and teachers. We thought that the experience in education would provide our interviewers with the ability to establish and maintain rapport with both the parents and the teachers with whom a collegial relationship might be established. The difficult job market for teachers during this time provided us with the ability to secure interviewers who had at least a bachelor's level teaching degree.

We were especially concerned about our ability to interview hyperactive children. We observed interviews of hyperactive children by personnel in the Reading Center and Clinic of Western Michigan University. From these observations, as well as from perusal of the literature, we developed a set of specialized techniques that we imparted to our interviewers in the training. These we imparted to a specially selected group of interviewers during intensive training sessions to prepare them to interview the hyperactive children.

Since we believed that the status differential between interviewers and physicians might preclude good interviews, we decided that all interviews with physicians would be done by the principal investigators or by trained interviewers with doctoral degrees. The interviews with physicians would contain questions that dealt with medical judgment and conduct, and thus it seemed to us that these questions would best be asked by someone who carried the title of "doctor."

Prior to the pre-test, we conducted a two-day training session with the interviewers to equip them with the skills and information needed for the conduct of the interviewing. We used the training session to inculcate in the interviewers a sense of the sensitivity of the interviewing process and the need for preserving the confidentiality and security of the data. We also provided training with the instrument schedules so that the interviewer would be able to administer the schedule in a sensitive and a competent manner (see Appendix C for a description of the interviewer training).

The interviewer training had two other functions for us. It enabled us to try out the interviewing schedules--to run through them as we conducted practice interviews--and as a consequence we refined the instruments by smoothing out the format and eliminating ambiguity and awkwardness in the items. We

also used the interview training session as a screening process to select those persons most capable of handling the interviewing. As with all other aspects of the pre-test procedure, the training and selection of interviewers were to be used as tests of the procedure itself in the comparable phase of the major study.

A report was provided to the Kalamazoo Public Schools after we had collected the data. This report dealt only with the prevalence aspect of the study from the mail questionnaire data. We had too few cases from the interview stage of the study to provide other useful data. (See Appendix D for a copy of the pre-study report.)

Following the completion of the pre-study we once again revised the instruments. At this stage the revision was very comprehensive and thorough. We found that some of the instruments we had developed were too cumbersome.

During the Kalamazoo pre-test study we had nine different role inventories (one for each combination of phase and sample). Each subject was taken through three role inventories, one for him or herself (i.e., the parent was asked to respond to the role instrument in terms of the expectations of parents) and one for beliefs about the role of the adults in the other two social systems. We abandoned this format and developed a role inventory which could be used for all subjects and all phases. The instrument that we developed as a result of this review was brought once more before our consultants and additional revisions were made.

We had decided to request permission of the subjects to tape the interviews so that we would have a basis to verify the completed interview schedules. The tapes were also a useful means of ensuring quality control of the interviewers. In addition, listening to these tapes gave us a good understanding of some of the defects and problems in the instruments that we had developed. This understanding was further enhanced by the debriefing sessions held with the interviewers. Their perception of the areas in which the interviewees failed to understand what was being asked them, in which rapport dissipated, in which fatigue set in, were invaluable in the instrument revision process.

The Logistics of Data Collection

At this point we began the selection process for interviewers for the Grand Rapids study. The Western Michigan University Employment Service, the Grand Valley College Employment Service, the Michigan State Employment Service, the Aquinas College Employment Service, and the Michigan Employment Securities Commission set us names and addresses of potential interviewees who met the criteria we had established during the pre-test in Kalamazoo.

Approximately fifty prospective interviewers were contacted

and were interviewed by members of the research team in a preliminary screening. We screened out those who were working as substitute teachers in the Grand Rapids Public School system, those who appeared to us to be inappropriate interviewers because of their manner, and those who appeared to manifest strong emotional responses to the subject area of the research. Thirty candidates were selected and began our training procedure for interviewers. The training procedure for interviewers was conducted in Grand Rapids during a three-day period.

The candidates were instructed in the nature of the research, general interviewing techniques and objectives, and the special problems that might be encountered in this research. In the final day of training each of the candidates conducted a practice interview with one of the investigators and some were eliminated. Twenty interviewers were hired.

As we developed the interviewer training sessions we took note of the need to develop proper attitudes. We were aware of the propensity of interviewers in large scale researches to develop casual or sloppy habits because they felt "it doesn't matter anyway." We worked very hard to develop, in the interviewers, a protective and responsible posture toward the interviewing process. We stressed that it represented the most critical and culminating stage of a research process that had taken several years. Further, we impressed upon the candidates that the research itself was intended to benefit children and their families, many of whom were enduring considerable difficulties. We impressed them with the fact that the respondents in this research were sharing with us painful, important feelings and information. The fidelity of their interviewing, then, was crucial not only for the process of the research but for its human objectives. In essence, we strove to make the interviewers feel not as if they were "hired hands" in the research project, but rather important members of a research team.

The interview training session provided another test for the interview schedules. Once again we found semantic and substantive problems in the interview schedules as they were administered. Many defects in the instruments were remedial.

Mailed Questionnaires: Coterminously with the interview training, the mailed questionnaires were sent to the parents of all of the students in one half of the elementary, middle, and junior high schools in Grand Rapids. The response rate to this mailing was 66%. We were informed that this was the highest recorded response rate to mail questionnaires in the history of mailed questionnaires to parents of that school system. We had hoped to achieve an even higher response rate, but we were satisfied after analyses of the non-respondents that we had an adequate representation of our population.

Our return rate was critical since we knew that we were

capturing a phenomenon which was, in absolute terms, quite low. Assuming a three to five percent rate or prevalence of hyperactive children, it was necessary for us to have a large response to capture a sufficient number of hyperactive children for subsequent aspects of the research.

At the same time, we mailed our questionnaire to all the teachers in the selected Grand Rapids schools. The mailing to the teachers encountered some unanticipated difficulty. We discovered that the second mailing to the teachers that had gone out that day, which was to have contained the questionnaires, had been mailed without the questionnaires. Upon discovery of this, we telephoned each principal informing them of our mistake. We developed a second "second" mailing to the teachers which contained a note of apology along with the questionnaire and we asked the principals to inform the teachers that we had caught the mistake, and that the first letter they received which erroneously referred to an included questionnaire should be disregarded. A second letter, which arrived the next day, contained the questionnaire. Subsequent to the delivery of the second letter, we did receive some calls and notes from teachers - some harsh, others reflecting puzzlement. We felt that we had rectified this mistake. Our subsequent contacts with teachers and the return rate, which was 73%, reassured us that the unfortunate error had not placed the study in any major jeopardy.

Responses to the mail questionnaire were secured through a process developed by Robin (1964). This involves a series of five possible mailings. All respondents received a prequestionnaire letter in which the purpose of the study was conveyed, a rationale for responding provided and the reader altered to the fourth-coming questionnaire. The second letter to the respondent contains a cover letter, questionnaire, and self-addressed envelope. The third letter, sent only to non-respondents, urges a response. A further mailing to those not yet responding contains a letter, another questionnaire, and another stamped, self-addressed envelope. Finally, those who have not yet returned their questionnaire received a fifth letter. These mailings were received a week or less apart. The content of the second through fifth letters changes gradually in emphasis: the first letters stress the importance of the research; the later ones, the importance of the respondents.

We attempted to confine our follow-up letters to those teachers who had not returned their questionnaires. This presented a problem since, in addition to all data being confidential, all of the responses were to be anonymous as well. To achieve this we used the technique developed by Glock and Stark (1966). This involved enclosing a postcard, self-addressed and stamped, on which the respondent wrote her or his name and indicated that she or he had returned their questionnaire separately. This postcard was dropped in the mail and checked against the master list of teacher sample. This process provided, sequentially, the

mailing lists for the third, fourth, and fifth contacts.

Obtaining the Sample: A three step process was developed in order to secure the sample for the parental interviews. The first step involved a screening of all returned mail questionnaires to determine if there were any positive responses on any of the items indicating that the child had been medically diagnosed as hyperactive. This was done by a staff member. The second step involved one of the principal investigators inspecting all of those questionnaires that had been flagged to see if there was sufficient data on the questionnaire to warrant further investigation. We excluded many children from our sample at this point because the first step had been a very rough screening and thus there were many children who were receiving treatment or had some sort of condition reported which was in no way associated with the hyperkinetic child syndrome.

If one of the principal investigators felt that there was sufficient reason to believe that the child might be designated as hyperactive, then this questionnaire was carried to the third stage. The third stage involved a phone call to the parent to verify that the child had received a medical diagnosis for hyperactivity. In this case an interview with the parent was arranged. We found that our initial belief that the determination of a medical diagnosis would be an explicit phenomenon was more problematic than anticipated.

The interviews normally took place at the home of the parents. Occasionally they were scheduled, at the request of the respondent, elsewhere in Grand Rapids. Interview packets with the proper interview schedule and all other needed materials were delivered to the Grand Rapids Public Schools - Western Michigan University Center for Educational Studies. The interviewers, after being informed of their interview schedule, picked up the appropriate interview materials and left completed materials.

Quality control of the interviews was ensured by a procedure in which the investigators listened to the taped interviews and evaluated the interviewer's performance. (See interviewer quality control form in Appendix E.) The interviewer was then contacted by telephone by one of the principal investigators and the interview rating discussed with the interviewer. This quality control procedure helped us correct problems of interviewing. In some cases interviewers received more formal retraining and a half dozen or so were terminated after their first or second interview(s). We were especially concerned that interviews which reflected high quality interviewer procedures be acknowledged by us and that we provide positive reinforcement for such interviews. The relationship between the principal investigators and the interviewing staff constitutes an important factor in the excellence of the interviews. We found it useful to talk with interviewers about experiences, observations, and feelings generated by the interviewing process. These conversations provided us with in-

sights and understandings that enabled us to make modifications in procedures and to alert us to findings of consequence. Also, these conversations demonstrated to the interviewers the importance of their functioning and a realization that completed interviews were not falling into limbo.

Several interviewers encountered difficulties and unpleasant experiences during the conduct of the interview. One interviewer, for example, was accused of displaying racist attitudes even though, upon review of the tape, there was little in what was said or done to warrant such accusation. The problem we faced during this stage of the research was handling the logistics, the substantive aspects of the research, and maintaining sufficient proximity to the conduct of the interviews to ensure the quality of data.

The interviews with the teacher, the physician, and the child were arranged after the parental interview was completed. At the conclusion of the parental interview, the interviewer asked the parent if she or he would permit the research team to contact the child's teacher, the child's physician, and the child in order to conduct a similar interview. The majority (92%) of the parents agreed. The parents were asked to sign a special form (see Appendix F) which provided written consent to set up the additional interviews.

The teachers were contacted by our office staff to schedule their interview. The teachers were informed of the nature of the research, of the parents' permission to contact them, and of the public schools' permission to conduct the research by interviewing them. The teachers were usually interviewed in the schools, during their break or after school. The question of the most appropriate teacher to interview posed a problem in some instances. We determined which teacher to interview by examining the case and, in some instances, by checking back with the parent to get more information about the child's classroom assignment and, in other instances, by seeking advice from the central office to enable us to determine which teacher would have the most complete information about the child in question.

The physician interviews were secured by making contact with their office after they had received a letter informing them about the research and providing other information necessary to get their cooperation. The physician interviews were usually conducted in the offices of the physician. In several instances, physicians who had been involved in the treatment of the child in our sample had moved from the Grand Rapids area. We made efforts to secure interviews with physicians whenever it was feasible even if they had moved out of state. In most instances we were able to secure the interviews with physicians who had moved. In a couple instances, the physicians who had moved felt that they had insufficient contact or recollection of the case and that even the securing of the records of the case would

not be of use in providing the response to the interview. When it was necessary to get an interview from a physician who had left the area (or in some cases the practice), we arranged with the practice that was currently holding the records for a copy of the records to be sent directly to the physician and returned or destroyed following our interview. Since the physicians constituted the smallest of the four samples in the research (because some physicians were treating a number of the children in our sample), we were particularly anxious to get interviews with physicians whenever possible.

The physician interviews required the most involved logistical arrangements. It is not customary for a receptionist in a physician's office to get phone calls arranging for interviews, thus a good deal of time was spent in making a number of calls and arranging the time and dates for the physician interviews. The physicians were remunerated for the interview at the rate of \$40 for the basic interview. Multiple interviews were prorated accordingly. In the case of a physician treating four children in our sample, for example, we needed to go through the sections of the interview which were child specific for each of the four children, but it was only necessary to go through the items which were general once.

In arranging the child interviews we had three concerns. The first of these was that our research would not in any way contribute to stigmatizing the child. We did not want the children who were included in our sample to be set apart from their peers by being singled out. It was important to us that the interviewing process not contribute to the problems that we perceived might occur for hyperactive children. A second concern was for the safety of the children and the maintenance of control over the children as they proceeded from their classroom to the interviewing situation and back to their classroom. A third concern was that the interview not result in a loss of important instructional time for the child. We did not want the interviewing to disrupt the child's educational program. In order to deal with these concerns, we worked with the building principals to assure that scheduled interviews did not interrupt instruction.

In a couple of instances, parents who had given their permission for their children to be interviewed requested that they be permitted to attend the interview or have an opportunity to hear the recorded interview with their child. Reluctantly, we allowed a few parents to sit in on the interviews (silently). We did not allow parents access to interviews conducted in their absence since we felt this would constitute a violation of the confidentiality of the child. Some parents accepted this when explained to them and permitted us to conduct the interview. In other cases it resulted in the loss of an interview.

We selected the child interviewers by securing the best and most appropriate interviewers on our staff. We reviewed the

interview control form, selecting the best interviewers and reviewing a sample of tapes from the candidates. We chose six of eighteen available interviewers on our staff and provided additional interview training during a one-day session. The child interviews were done exclusively by this team of interviewers and there were no instances of difficulties or complaints arising from the child interviews.

Data Management: The coding of the interviews presented us with a very substantial task. We had approximately six hundred complicated and sensitive interviews to code. Even though many of the items were closed-ended and response categories were provided, we encountered many variations in response which required us to develop additional coding categories. Other procedures for coding the data had to be developed for open-ended and unusual questions. We developed rigorous procedures for quality control of the coding process. These procedures involved double coding of interviews, the monitoring of all coded interviews, and special training of personnel, coding supervisors, to adjudicate ambiguities and make decisions in a consistent and rational fashion.

All coders underwent a formal period of training prior to being entrusted with the coding process. During the training the principal investigators made a presentation in which they attempted to instill a sense of the importance of the coding process in the conduct of research. New coders had special quality control checks upon their work built into the coding process.

The coding of data for projects such as this is an arduous and monotonous task. We were concerned that sloppy work habits might develop as the task wore on. Consequently, we developed a quality control process for coding in which quality control procedures were increased toward the end of the task (see Appendix G). Several times we met with the coders, discussed the coding process, and tried to do and say the things required to maintain a high level of morale during this cumbersome stage of the research. On several occasions we brought the staff to a luncheon at which time we reviewed for them the process of the research and secured feedback from them about the coding process. Once again we found that the information obtained from them was invaluable to us. Often they would express reluctance to provide criticism or comment because they felt that we were aware of it or that it was inconsequential. In several instances, however, these comments provided extremely helpful information, enabling us to identify and surmount problems in the coding process.

We coded the data onto mark sense sheets as an interim stage in the process of developing computer data files. This procedure was chosen rather than using direct access to tape in order to improve our ability to check the data for errors and to enable us to employ a larger work force to code the data as rapidly as possible.

In transferring the data to the computer we recognized that, in some instances, the actual words of the interviewee were required to capture the flavor and full meaning of the comment. Thus, we instituted a process called "data sweep" which consisted of a review by the principal investigators of every interview to determine which segments of the interviews should be transcribed. The data sweep was also used for those questions in the interviews for which precoded answers were inappropriate and for which a content analysis was required prior to the extraction of data from the interviews.

After the data were "cleaned" and organized in data files, the principal investigators reviewed the array of data case by case in a process called "final adjudication." In this process all cases were examined for anomalous data, and to provide the ultimate phase classification. In some cases decisions were made about case retention in the sample. It was at this point that the final sample was determined and that the phase categorization of each case made.

Researcher as Resource

In conducting this research, we sent out almost eleven thousand questionnaires to parents in the Grand Rapids community to elicit information about behavior and learning problems of their children. Our reason for sending these questionnaires was to secure data about those problems which would enlighten us about the diagnosis and treatment of hyperactive children. While this was the intended function for the research, it served another purpose. The questionnaire focused attention for some parents on conditions and problems which were causes of acute concern. The questionnaire for these parents was seen not as a means of providing information for researchers but rather as a potential avenue for getting help. The act of asking the kinds of questions in the questionnaire led some to perceive us as a resource.

As the parents returned their questionnaires, we noted on many of them requests for information or assistance for problems that they described in greater detail than called for by the questionnaire. It was impossible to cast these aside as tangential or irrelevant to the research. We had intruded ourselves into their lives and felt responsibility for the consequences of this intrusion. At the same time we recognized that our first obligation was to achieve the goals of the project. We were aware that the limitations of our resources and capacities posed limitations in our ability to respond. Our resolution of this was to serve as a broker. We attempted to steer individuals in a direction where they might receive help from the resources within the community and the school system.

Many of the parents experience great difficulty in navigating the organization of schools and agencies when they are seeking help for chronic problems. We had not counted on spending time channeling persons to places where they might receive help yet, indeed, felt an obligation to do so. We had become a resource within the school system and community and we tried to provide help - not by giving primary care - but by providing responsive and compassionate assistance to those who contacted us by letter and phone during the course of the research. Research in a sensitive human area, we were vividly reminded, should generate a sense of obligation that must be carefully discharged by the researchers.

These experiences alerted us to another related problem in the research. It occurred to us that, in the process of interviewing, parents and teachers might see the interviewer as a resource for information on hyperactivity. Our task was to provide a procedure for dealing with questions from interviewees, (i.e. "Is the Finegold diet effective?" "Will Ritalin retard my child's growth?") so that our interviewers could respond in an ethical manner that would preserve the rapport needed for effective interviewing.

We dealt with this by setting up a series of meetings for parents and teachers who had identical and educational questions about hyperactivity and its treatment. Parent and teacher respondents were informed of these sessions when they raised substantive questions with the researchers. They were invited to attend by the interviewers. The first session was held for parents and teachers in the Kalamazoo area as a result of our pre-test data gathering activities. Two other sessions were held in Grand Rapids at the termination of the data-gathering activities there. Parents and teachers who attended these sessions were able to discuss their questions with experts.*

Dealing with Sensitive Issues

One of the members of the NIMH site visitation team involved in our professional review had been involved in an episode in Massachusetts which led to the passage of state legislation prohibiting research dealing with psychoactive medication for children. He informed us again and again that research of the type that we were proposing was difficult if not impossible to conduct. It was his belief that the climate was such that research dealing with the treatment of psychoactive medication for school children generated such controversial and volatile issues and problems that the conduct of our research was infeasible.

*We wish to thank the participants in these sessions for their time and help. They are: Samuel Stauffer, M.D., Edward Birch, E.D.D., Mark Hinshaw, M.D., Donald Waterman, M.D., William Reeves, and Garret Vander Lugt, E.D.D.

This experience sensitized us further to what we had recognized--that this research could indeed be aborted because of controversy; thus, it was necessary for us to develop procedures and techniques to guard against this possibility. We recognized that, even with careful development of procedures to offset the sensitive nature of the research, it was possible that the study could be disrupted. But we were convinced that we, through our actions, could have an impact on the probability of this occurring. The most important set of actions, we felt, were preventive in nature.

Throughout this research, we kept reminding ourselves of the need for candor and complete public disclosure about what we were doing, what we intended to do, and why we were doing it. We felt that this was the best insurance for the successful completion of the research. We avoided the temptation to be coy and secretive about our activities. If the research were to be disrupted, we preferred it to be because of a response to accurate information from us rather than rumor and conjecture.

In implementing this policy, our communications with parents, teachers or physicians included the invitation to contact us by phone with any questions or concerns that they had about the research. We set up an incoming, toll-free WATS line so that persons from Grand Rapids could easily avail themselves of our invitation. During the course of the research we received hundreds of phone calls on this toll-free line. Many of these calls dealt with fairly routine matters. Perhaps the most common was the belief of some parents who received the questionnaire that we had reason to believe that their child had some behavior learning problem. Although the sampling procedure was explained clearly in the letter to them, many parents were anxious enough to want to double check this point.

Our staff was given instructions on how to deal with this and other such routine questions (e.g., information about where to send the questionnaire, request for another questionnaire to replace one that had been lost, and so on). The staff was further instructed to channel any non-routine calls to one of the principal investigators. At all times during the course of the data gathering process one of us was available to take calls. These precautions also extended to contacts the staff initiated with the respondents (e.g., checking out information, setting up interviews, times and schedules, and so on.) If they encountered any problematic interactions or any expressions of anxiety, hostility, or need for information beyond their knowledge, we handled the call. As a result of these precautions, there were extremely few irate, unmollified responses by parents and teachers.

In research of this nature it is important that interviewers realize how seriously the investigation considered their pledge of anonymity and confidentiality. No agency had access to identifiable data or the names of the respondents. In an attempt to provide maximum security, we established a procedure whereby no

more than one member of a set (parents, teachers, physicians or child) would be interviewed by a given interviewer. The scheduling had punctilious surveillance to make sure that no interviewer would be in a position to provide one member of a set with information given that same person by another member of the same set. We wanted to eliminate deliberate or accidental breach of confidentiality by removing the interviewer from the possibility of becoming a conduit between parent, teacher, physician or child.

During the course of interview training, it became evident to us that some means of dramatizing the seriousness of the confidentiality was necessary. One of the prospective interviewers during our training session was quite concerned about the requirements of state law upon teachers to provide information pertaining to child interviews. Michigan had recently enacted legislation providing that individuals in certain occupations, among them teachers, are required to furnish information about child abuse to authorities. This interviewer trainee anticipated a situation which could possibly leave her with the obligation to furnish such information to the authorities. It was our belief, verified by checking with legal counsel at our disposal, that our primary responsibility was to protect and preserve the confidentiality of the data and the anonymity of the respondents. As a result of this experience, we recognized the need to ensure the confidentiality of the data by requiring all interviewers to sign a pledge of confidentiality (see Appendix H).

Access to data was another concern stemming from our understanding of the sensitive and volatile nature of the research. We established very elaborate procedures to guard the integrity of the data. All data were stored in locked cabinets, and access to these cabinets was limited to the principal investigators, the administrative assistant, and our three data supervisors. No data coder was permitted to access data other than the data being coded. All coding was done in a room wherein access also was limited. The first step in the process of making the data computer sensible involved the removal of all identifying information from the interview. No accessing of computer files or data banks can result in the identification of any of the respondents.

These procedures were designed to meet problems of the project respondents and research staff. A set of similar activities were undertaken to attempt to head off potential problems at points where the research would intersect with the larger community and with the involved medical and educational communities. In anticipation, we attempted, well before the data gathering phase of the research, to acquaint all who might be concerned and alert to this research with the fullest possible information about the research and about their possible participation in it. We requested and received permission to speak to the principals' meeting of the Grand Rapids Public School system. At this meeting, we explained the nature and intention of the

research. We explained the proposed participation of teachers and students. We talked about the interview schedule and the mailed questionnaire in detail. We attempted to defuse hostility or anxiety on the part of the principals.

There was some concern expressed by principals about the research. Principals are involved in many different programs and they feel that there are many "lay ons" imposed on them. As this meeting progressed, we found an increasing level of hostility toward our activities. At a very critical point in the meeting, one of the key administrators of the school system made a very strong statement of endorsement for the research explaining that he had a hyperactive child and that he, as a parent, was aware of the problems that we were seeking to address (The investigators were unaware of this to this point.) and that the cooperation of the school system was highly desirable. This comment by a person who was respected and powerful turned the tide. Throughout the research we enjoyed a positive relationship with principals.

We also contacted other key administrators in the school system. We met with them and explained what we were attempting to achieve through the research and how it would proceed. Since the conduct of the research required the cooperation of the teachers, we met with the chief administrator of the Grand Rapids Public Schools Educational Association and informed him about the research. He brought a description of the research before the Executive Board of the GREA and this organization authorized teachers to participate if they so chose. The amount of cooperation required for successful completion of this research from school administration, from the individual school building personnel, and from the individual teachers was enormous. It is our strong belief that, given the apprehension about this topic, it would have been impossible without these measures to gather the data needed to conduct the research.

Of equal importance were contacts with the medical community of Grand Rapids. We met with the pediatric sections of the two major hospitals in Grand Rapids. Jointly they accounted for the majority of practicing pediatricians. At these sessions we described the nature of the research and explained the participation that we needed to obtain from the medical community of Grand Rapids. We also contacted persons connected with family practitioners in Grand Rapids to assure that communication with this group of practitioners would take place. Shortly before beginning the interviews, we had a description of the research published in the Kent County Medical Bulletin (see Appendix I).

In instances where there were questions about the credentials of the investigators to conduct the research or other matters that involved sensitive issues for the medical community, we were able to get the assistance of a prominent Grand Rapids physician who answered questions and concerns from his colleagues. In essence, this person served as a hotline for us to the medical community of Grand Rapids.

During the most active period of data gathering, in spite of our best efforts, two untoward events did occur that had the potential to threaten the success and continuation of the research. Shortly after the questionnaire had been mailed we received a call from a person who was concerned about the research and requested more information. He told us that he had heard we were working with the school system to identify children who had undiagnosed minimal brain dysfunction. It was his understanding that we would tell the school system who ought to be diagnosed as minimally brain damaged. We informed him that such was not the case. We told him that while we hoped to provide information that would lead to an improvement of procedures and policies in the Grand Rapids school system at no time could we nor would we supply information pertaining to specific children; moreover, no diagnostic or screening activities were a part of the research.

The caller then requested more information about steps which would follow the mail interview stage of the research. We described in detail each of the procedures that we followed after the questionnaires had been processed and after we had identified the children who had been diagnosed as hyperactive. At this point he expressed concern that we had misled our subjects. He told us that none of the letters which accompanied the questionnaire described in sufficient detail the interview stage of the research. Our response was that we had made the decision concerning level of detail in the questionnaire based on the fact that the interviewing would involve a very small percentage of those who were recipients of the mail questionnaire. We informed him that we planned to recontact those whom we would interview and, if for any reason, those parents were unwilling to grant us an interview, the request would be dropped without any questions asked. We did not see this as a breach of ethics.

Two days later we received a call from a reporter at Channel 13 in Grand Rapids about our research. She told us that she had been contacted by a representative of the American Civil Liberties Union (ACLU). The ACLU was concerned about the violation of constitutional rights of our respondents. Given the content of her remarks it seemed highly probable that our previous caller was the representative of the ACLU.

The reporter wanted to send a news team to interview us. We realized that adverse exposure on television could jeopardize or even cause termination of our research. We informed the reporter that we would be available for an interview but asked that in addition to us that there be some representation from the school system. Many of the concerns that the person from ACLU had raised involved the school system's posture and use of the research; it was our belief that a school system representative should speak to these issues. We were prepared to deal with all aspects of the research, but could not provide first-hand information about the school system's involvement and use of the research.

A television interview, under these conditions was conducted. We and the school officials responded to the questions and described what we were doing. The story was presented as the first news item of the local Grand Rapids news on the 6 o'clock news. The handling of the story, however, was very positive and supportive of our research. The reporter was convinced that we indeed were not planning on identifying minimal brain damaged children for the school system unbeknownst to the parents of the children and that what we were trying to do was not improper. The news story concluded by advising that if parents were willing to take the time to fill in questionnaires this information could well be useful to the school system. The incident coincided with an increased wave of mail questionnaire responses contributing substantially, we think, to the total response rate. The ACLU wrote a letter to the school system informing them that they were troubled by the research but they took no further action.

The final incident had its genesis prior to the initiation of the research. In 1975, the popular author Vance Packard contacted us by mail about early research we had published about the attitude of teachers in the Grand Rapids Public Schools to the use of Ritalin. We had responded to Mr. Packard by sending him copies of work, by corresponding with him in detail and by reviewing not only his presentation of our work but the entire section relevant in his publication The People Shapers. For this we were given special mention and thanks.

As the data collection phase was concluding in the late spring of 1977, Vance Packard went to Grand Rapids to give a public lecture. In a television interview he indicated that the school system was avidly pursuing the medication of hyperactive children and he cited our research - incorrectly - to support his contention.

Upon being alerted to Mr. Packard's presentation on Channel 8, we contacted the show host and were invited to appear on his program. During our presentation we corrected the misinformation. We also used the occasion to discuss other aspects of the research and to express our appreciation for the collaboration of the Grand Rapids Public School system, the parents, physicians, and children. There were no untoward incidents as a result of this television exposure and no repercussions that we were aware of.

CHAPTER FOUR

NATURE OF THE SAMPLE AND PREVALENCE OF HYPERACTIVITY

The purpose of the mailed questionnaire as described in Chapter Three was twofold: one purpose was to provide some indication of the prevalence of hyperactivity and a measure of the ways in which hyperactivity was being treated in the Grand Rapids Public School system; the second purpose was to secure a sample of hyperactive children in order to interview their parents, their teachers, their physician and the children themselves. In order to do this, we sent the questionnaire (as described in Chapter Three) to all parents of the children in half of the elementary, middle and junior high schools of Grand Rapids, Michigan. A total of 10,803 questionnaires were mailed. We secured 7,235 usable responses or 67%.

At the same time we sent the teachers of the same schools their questionnaires as a check on the prevalence rate. Of the 570 questionnaires mailed, 417 (73%) were returned.

An analysis of the questionnaire from the parents yielded 5,827 "negative" returns, that is, children with no sign of diagnosed hyperactivity; 1,186 "false positives," those questionnaires about children who appeared possibly to have been diagnosed as hyperactive and required further follow up and verification; and, ultimately, 229 "positive," those children who appeared to have been diagnosed as hyperactive. The analysis of prevalence and treatment was made on the 229 children, though some small refinements were later made in the interview sample.

We have noted in our discussion of the controversy surrounding hyperactivity and its treatment that there are medical, technical, political, and moral questions that have not been answered. One such "technical" question, and an important one is: What is the prevalence of hyperactivity? Related to this question is the issue of the frequency of various types of treatments for hyperactivity. Since much controversy has involved allegations of promiscuous diagnosis of hyperactivity (or related diagnoses) and treatment with stimulants, the nature and quality of the data about prevalence are extremely important. Further, reliable information on prevalence could be useful in addressing questions about the etiology, epidemiology, and needed scope and nature of medical and educational programs and policies for the welfare of hyperactive children.

One of the first major public confrontations on the issue of prevalence of hyperactivity occurred eight years ago before the House Subcommittee of the Committee on Government Operations (Gallagher, 1970). At that time, essential information was unavailable to expert witnesses. The transcript of the testimony before the House Subcommittee illustrates how inexact was the information on prevalence in 1970.

Mr. Rosenthal. Could anyone tell us what is the professional estimate, as to the number of children in the United States that may be affected by MBD disorders?

Dr. Lipman. Based on the percentage figures that we have seen, which have ranged from roughly 3 to 10 percent of the school age population, we would estimate somewhere between about $1\frac{1}{2}$ to 3 or 4 million children. Based on surveys.

At another point in the hearing a related issue was considered: the extensiveness of the use of stimulant medications for the treatment of hyperactive children.

Mr. Gallagher. How many children would you say today are being treated - we have seen quoted a figure of some 200,000 to 300,000 children. Would that be correct? More? Less?

Dr. Lipman. Well, if you restrict it to amphetamine and to Ritalin, I would say that figure is probably high. It would probably be closer to about 150,000 to 200,000. That is just a rough estimate, Mr. Gallagher.

Mr. Gallagher. Now, further, the man who gives that figure, Dr. Lipman, who we are speaking to here, you said that perhaps 300,000 children are now on the --

Dr. Lipman. This is incorrect. The figure I presented had 200,000 as an upper limit.

Mr. Gallagher. Then further you state, "I think the results of the last few years of research will soon reach the Nation's doctors. The pediatricians will begin using them." In effect, what will happen is it will zoom as word of its success spreads throughout the Nation's medical community.

Where do you think it will zoom to 5 years from now?

Dr. Lipman. I didn't use the term "zoom." I said it would probably increase.

Mr. Gallagher. I think your enthusiasm led to the word "zoom."

Dr. Lipman. I guess really some evidence that we have indicates that child psychiatrists tend to be using more of the stimulant drugs than pediatricians. I think the more recent studies that are well controlled and meet scientific standards have strengthened the earlier clinical reports and I think as the scientific validity of the treatment of children with hyperkinesis with the stimulant drugs as part of their total treatment program

becomes better known and better accepted by the medical community, that there probably will be some increase. Now, where it will go, I don't know.

Mr. Gallagher. Do you think it should be allowed to increase or zoom or whatever word we want to use, on the basis of the follow-up studies which involve, as I recall, some 250 children out of 200,000 or 150,000 or 300,000, whatever is the correct figure? Are we justified at this point in further funding the use of amphetamines for children?

Dr. Lipman. Well, I think there are many gaps in our present knowledge. (Gallagher, p. 16)

Previous Research on the Prevalence of Hyperactivity

An examination of the research literature on the prevalence of hyperactivity reveals why the expert witnesses had difficulty testifying in 1970. Unfortunately, the research conducted subsequently provides no firmer basis for our understanding of prevalence.

Huessy (1967, 1974), Huessy and Gendron (1970), and Huessy, Marshall, and Gendron (1973), in research using teachers' ratings, found the rate to be between 10% and 20%. Werner, Bierman, French, Simonian, Connor, Smith, and Campbell (1968) reported 8-9% of the boys and 2-3% of the girls manifested "hyperactive symptoms," while Miller, Palkes, and Stewart (1973) concluded that 9.3% of the boys and 1.5% of the girls were hyperactive on the basis of a study of teachers in St. Louis. Cantwell (1975b) and Wender (1971), generalizing from a series of studies, placed the rate between 5% and 20%, Stewart, Pitts, Craig, and Dieruf (1966) placed the rate at 4%, Renshaw (1974) at 7%, Office of Child Development (1971) at 3%, and the Staff Report of the Education Committee of the California State Senate (1974) at 15%.

The lowest reported prevalence of which we are aware comes from Lambert, Sandoval, and Sassone (1978) who conducted a study of 5,000 school children, grades K-5, in 146 schools in two counties of California. The researchers gathered data from the home, physician, and school, and after a process of integrating these data sources concluded that the prevalence rate was 1.19%. (Whalen and Henker, 1980)

Some of the confusion in estimates results from misinterpretation of the literature. Even though Lapouse and Monk (1958), for example, do not draw a one-to-one relationship between maternal reports of the symptom of overactivity and the diagnosis of hyperactivity, such misinterpretation occurs. Adding to this type of confusion are difficulties resulting from several methodological or conceptual problems.

Methodological Problems in Prevalence Studies

One of the most critical problems that besets attempts to estimate prevalence is the population/sample problem. Lambert et al. (1978) used a two-county area from which to solicit cooperation from school districts. Other researchers have used counties or individual schools as samples or have relied upon convenience or ad hoc samples. In studies with such samples, the problem of determining what the prevalence estimate reveals is severe since a discrete, meaningful population may not have been defined. Since there is reason to believe that differences in the prevalence of hyperactivity may be associated with demographic characteristics, this shortcoming may be critical.

Other sampling problems center around the definition of population at risk. Almost all researchers gather data about school children, but some studies are confined to elementary schools while others stop at relatively arbitrary points such as the 5th grade or age 11. It is essential, therefore, to define the population to which rates are being generalized. If the definition of the population is unrealistic in terms of the population at risk, then the limitations of the research are evident and the risks of improper generalization clear.

In counting hyperactive children, we are engaged in an activity which is quite different from the calculation of other rates such as deaths, highway accidents, or even many other types of medical diagnoses (e.g., cancer, heart disease, etc.). In reality, there is not a single population of hyperactive children but many populations. Each population is an artifact of the criteria used to consider a child within the category. There is no standard definition of the pathology, and various types of persons (physicians, teachers, social workers, psychologists) may categorize children as hyperactive using a variety of procedures or approaches. Unfortunately, much of the previous research in this area has been conducted without explicit consideration of the alternatives involved in placing children in the category of "hyperactive." In counting hyperactive children, some researchers leave the impression that their approach is the only viable one or accounts for the "real" hyperactive children.

Even if we are explicit in our definition of who is placed in the category and recognize it as a stipulative rather than a real definition, there is another problem in counting hyperactive children. Should a 14-year-old, diagnosed as hyperactive at age 6, be counted as hyperactive? Should he be so categorized if treatment has been discontinued for two years - four years? No single prevalence rate is sufficient since medical procedures for pronouncing the child no longer hyperactive are often vague, invisible, or nonexistent. Thus, what is required are several rates describing the different social and medical meanings of the condition.

Given decisions about the criteria for inclusion within the category, it is still necessary to determine which reporting

Table 4.1

Various Estimates of Prevalence of Physician-Diagnosed
and Treated Children in the Grand Rapids School System

Group	Parent Source (7,248)		Teacher Source (9,293)	
	f	%	f	%
Ever Diagnosed				
Unverified	229	3.16	314	3.38
Verified	212	2.92	-	-
Treated within past 5 years	130	1.79	-	-
Currently being treated with stimulants	52	.72	75	.81
Ritalin	46	.63	70	.75
Dexedrine	1	.01	1	.01
Cylert	5	.07	4	.04

For reasons previously discussed, no single prevalence rate is adequate. Our first estimate of "ever diagnosed (unverified)" is calculated from information derived from the parent and teacher questionnaires. The estimate from teachers is .2% higher than that from parents. This estimate refers to all children who have ever been diagnosed by a physician as hyperactive. Children recently diagnosed and currently treated, children diagnosed many years prior to the collection of data and no longer being treated, and children with long-standing diagnoses and still being treated. The rates of 3.16% and 3.38% represent the highest possible prevalence rates obtainable from our data, and we feel they are over-estimates of the functional prevalence of diagnosed hyperactivity in school systems.

As a result of our telephone calls to the parents of 229 children, 17 were found not to have been diagnosed by a physician. The verified prevalence, therefore, is based on 212 children (2.92%). We were unable to produce the same type of estimate for teachers because of ethical restrictions.

Parent and teacher estimates of "ever diagnosed" prevalence were similar. Initially we were concerned about parental under-reporting and teacher over-reporting and, thus, the need to rectify

disparate rates. Given the data, these concerns appear to have been unwarranted.

Table 4.1 also contains data about the number of children who were treated for hyperactivity sometime within the last five years. This rate was calculated to provide an estimate of a functional prevalence - a somewhat more useful picture of the number of children in the school system who could be considered hyperactive. One might reasonably propose that a child who has not been treated in five years might no longer be considered part of the hyperactive child population. We found that 130 children, or 1.79% of the school population, had been treated within the last five years.

Since treatment with stimulant medication has been of special concern, Table 4.1 concludes with the prevalence of school system children being treated with stimulants for hyperactivity. Teacher and parent estimates were virtually identical. Based on these figures, between .7% and .8% of the children in the school system are being treated with stimulant medication. Ritalin accounts for almost all of the stimulants prescribed. Of interest is the fact that the newest stimulant medication, Cylert, has not been used as the treatment of choice to any appreciable extent.

In addition to the estimates presented in Table 4.1, we estimated the number of children in school, up to age 11, who were medically diagnosed as hyperactive. The number of children so identified is 94, which is 1.29% of the parent source sample. It is of interest to note that this number compares quite closely with the 1.19% rate produced by Sandoval, Lambert and Sassone (1980) for grades K-5.

In response to the question which asked teachers how many children they believed displayed the symptoms of hyperactivity, 340 children (3.65%) were indicated. These children were exclusive of the 212 identified as physician-diagnosed. In order to produce a comparable estimate from parents, we examined data from the Connors (1973) "Parent-Teacher Questionnaire" (10-item symptom check list) completed by parents in the sample. Two hundred eighty-seven children (4.96%), excluding those diagnosed as hyperactive, were rated two or more standard deviations above the mean (mean = 15.55; standard deviation = 5.40; score values 1 to 4; possible range 10-40). Thus, there is a tendency for both parents and teachers to identify a larger proportion of children manifesting the symptoms of hyperactivity than have actually been diagnosed medically.

Table 4.2 is a summary of the treatments for the physician-diagnosed children as reported by parents in our sample. This table shows that the most common treatment for hyperactivity was Ritalin.

Table 4.2

Summary of the Frequency and Percent of Children
Ever Treated (Verified) for Hyperactivity

Treatment	f	% of Hyperactive Children (212)	% of Total School Population (7,248)
Megavitamin Therapy	4	1.89	.06
Counseling	68	32.08	.94
Special diet	14	6.60	.19
Behavior Modification	22	10.38	.30
Psychiatric treatment	9	4.25	.12
Dextroamphetamine	17	8.02	.23
Mellaril	14	6.60	.19
Dilantin	7	3.30	.10
Cylert	8	3.77	.11
Phenobarbital	18	8.49	.25
Ritalin	158	74.53	2.18
Benadryl	10	4.72	.14
Valium	5	2.36	.07
Imipramine	7	3.30	.10
Coffee or tea	19	8.96	.26
Other	9	4.25	.12

Note. Since some children received more than one treatment, the totals and percentages for this table will not sum to the number of diagnosed hyperactive children or 100%.

Almost 3/4 of the physician-diagnosed hyperactive children were treated with Ritalin at some time. About 1/3 of the hyperactive children received counseling. Other treatments were comparatively infrequent; behavior modification was used for about

source(s) should be used to calculate a prevalence rate. There is reason to believe that multiple-source reporting of hyperactivity may be advantageous. In a situation in which we suspect that the prevalence rate is an artifact of the source of the data, independent sources, using common criteria for hyperactivity, provide a more complete description of the prevalence.

Previous Research on the Prevalence of Stimulant Treatment

Although the controversy about hyperactivity turns strongly on the use of stimulant medication, there is little known about the prevalence of stimulant treatment among school children diagnosed as hyperactive. A recent summary of this literature is found in Sprague and Gadow (1977). Much of the data is indirect. In the testimony presented above, Lipman speculated that between 150,000 and 200,000 children were receiving medication for hyperactivity (Gallagher, 1970). Greenberg and Lipman (1971) reported 91% of the physicians surveyed in the Washington, D.C. area prescribed psychotropic medication for hyperactivity. One-third of a sample of teachers in a Midwest urban area reported having one or more children in their classes, past or present, taking Ritalin (Robin and Bosco, 1973; Bosco and Robin, 1976). Scoville (1974), on the basis of 671,000 prescriptions written, estimated that 56,000 children were being treated (in 1973) with stimulant medication.

More directly, Sprague and Sleator (1973) calculated that 2-4% of the children in the Chicago School System received drug therapy for hyperactivity during the 1970-71 school year. Conway (1976) reports the percentage of children on medication for the treatment of hyperactivity ranged from .3% to 6.5% in 43 schools in seven counties of New York. Data from Krager and Safer (1974) indicated a prevalence rate of 1.07% of children in Baltimore County, Maryland, being treated with drugs for hyperactivity in 1971 and 1.73% in 1973. These data are not confined to stimulant medication. To our knowledge, the only research which provides information on alternate treatments and untreated diagnosed children is that done by Sandoval, Lambert, and Sassone (1980) (in Whalen and Henker, Chapter 5). Clearly, such data are needed to address questions about and charges concerning the misuse of medical diagnoses and medical treatments (particularly stimulant medication) and of inappropriate treatment and pressures from teachers and school systems.

Results

The data from parents and teachers constitute a report on the same population of children. The 8% difference in response rate, however, results in a larger number (9,293) of children reported by the teachers than by the parents (7,243). Table 4.1 contains information on the prevalence of physician-diagnosed and treated children.

10% of the children and over 8% had Phenobarbital prescribed at some time. From another perspective, however, these figures show how few children in the school population have ever been treated for hyperactivity by any of the methods: 2.5% have ever been treated with any stimulant medication, which is 3 1/2 times the proportion of those currently being treated (see Table 4.1). With the exception of counseling (.94%), no other treatment had been experienced by more than .5% of the total school population.

Table 4.3 shows the comparison of the hyperactive and non-hyperactive children with regard to personal and family characteristics. This table supports findings in other research that the preponderance of hyperactive children are male. Males outnumber females by almost 4 to 1 for our sample. This table reveals that there were significantly more hyperactive children (48%) than non-hyperactive children (36%) who were oldest or only children in their families, $X^2 = 12.03$, $p < .001$. However, if we compare the proportions of only children who were hyperactive and non-hyperactive, we see that they are very similar. Within the multi-child families, the proportion of oldest children who were hyperactive (36%) is significantly greater than the proportion of oldest children who were not hyperactive (27%), $X^2 = 8.82$, $p < .003$. A significant difference was also observed between the 15% of the hyperactive children who were fourth or later in their families and the 24% of the non-hyperactive who were also fourth or later, $X^2 = 9.74$, $p < .002$. We conclude that the best family predictor of hyperactivity in our data is the child's place within a multi-child family; being the first-born child is associated with higher rates of diagnosed hyperactivity while being born fourth or later is associated with lower prevalence.

One of the issues that has surrounded the question of hyperactivity has been the extent to which the diagnosis has been used as a means of suppressing lower socio-economic children. These children, the argument goes, display culturally differing patterns of behavior which become interpreted as deviant behavior and then as "sick" behavior to be diagnosed and treated medically (Conrad, 1975). There is additional support for the relationship between social class and the diagnosis and treatment of hyperactivity from an extensive collection of theoretical and empirical papers in the medical literature. Various conditions (e.g., malnutrition, inferior prenatal care, premature births, and so forth) have been linked to the presence of hyperactivity. (See Ross and Ross, 1976, for an excellent summary). Thus, there are several reasons to consider whether there is a relationship between hyperactivity and social class.

Table 4:3

Comparison of Personal and Family Characteristics of
Physician-Diagnosed Hyperactive and Non-Hyperactive Children

Characteristics	Hyperactive Children (n=212)		Non-Hyperactive Children (n=7,036)	
	f	%	f	%
Sex				
Male	167	78.77	3,513	49.93
Female	45	21.23	3,518	50.00
Missing Data	-	-	5	.07
Family size				
One child	25	11.79	641	9.11
Two children	51	24.06	1,642	23.34
Three children	66	31.13	1,762	25.04
Four - six children	62	29.25	2,454	34.88
Seven or more children	5	2.36	529	7.52
Missing data	3	1.42	8	.11
Mean family size	3.17		3.59	
Oldest and Youngest children				
Oldest child	102	48.11	2,553	36.28
Youngest child ^b	56	26.42	2,203	31.32
Place of object child in multiple-child families ^a				
Oldest child	77	36.32	1,911	27.16
Second child	54	25.47	1,705	24.23
Third child	25	11.79	1,109	15.76
Fourth or later child	31	14.62	1,669	23.72
Youngest child ^b	56	26.42	2,203	31.30

^aSince "only children" are excluded, the totals and percentages for this table will not sum to the number of children in the sample or 100%.

^bYoungest children are reported separately since this category is not exclusive of second child, third child, etc.

Using the Duncan (1961) measure of socio-economic status, we compared various subsamples of children. Table 4.4 presents these comparisons. Both mothers' and fathers' SES scores are shown.

Table 4.4

Means and Standard Deviations for
Socio-Economic Status (SES) Scores by
Treatment of Hyperactive Children

Group of Children	n*	Fathers		n*	Mothers	
		Mean SES	(SD)		Mean SES	(SD)
Hyperactive (N=212)	162	35.03	(22.94)	198	20.56	(22.47)
Stimulant treated (N=168)	131	35.85	(22.53)	159	21.83	(23.04)
Diagnosed/never treated (N=9)	3	19.67	(2.08)	6	13.83	(9.24)
Non-hyperactive (N=7,036)	5,462	37.74	(25.35)	6,508	20.13	(23.54)

*The number used for calculation (n) reduced from the number in group (N) due to single parent families and missing data.

As Table 4.4 reveals there are only very small SES differences among hyperactive children, non-hyperactive children, and hyperactive children treated with stimulant medication. While there are additional indicators of social class not used here, occupation, the single strongest social class indicator, does not reflect SES differences in the diagnosis and treatment of hyperactivity.

Table 4.5 contains a frequency distribution for the prevalence of the currently treated children by school:

Table 4.5

Frequency Distribution of Physician-Stimulant-Treated
Hyperactive Children

Prevalence of Currently Treated Children in Percentage	Number of Schools
.0 - .29	6
.30 - .59	5
.60 - .89	5
.90 - 1.19	5
1.20 - 1.49	5
1.50 - 1.79	3
1.80 - 2.09	0
2.10 - 2.39	0
2.40 - 2.69	1

Table 4,5 shows, for example, that six schools in the sample fell within the 0% to .29% range. Table 4.5 indicates that there is an appreciable amount of variability with regard to the extent of stimulant treatment. Four schools have a rate of treatment with stimulant medication roughly double that of the school system prevalence rate for treatment with stimulants. It can be seen that information about a school system in general may obscure substantial variations among schools within the system. An individual who insists on a finding of "a lot" or "very little" hyperactivity and stimulant drug treatment may be quite correct for that part of a school system to which the individual has access. However, that person may be quite wrong for the system as a whole and may reach a different conclusion than an individual viewing another part of the same school system. While we cannot explain the reason for the variation among the school rates of prevalence of currently treated children, one factor, the mean SES of all children's fathers by school, is not significantly associated with the variation in prevalence rates. In other words, schools with low SES levels do not have greater prevalence than schools with higher SES levels.

Samples for the Interviews

The parents of the 229 children (i.e., positive cases determined by prevalence analysis) were contacted for an interview. After the initial contact by telephone all of the 229 potential sets (parent, teacher, physician, child) were reviewed (this is the adjudication process referred to in Chapter Three). On the basis of the review of the mailed questionnaire data and the data gathered from the parents (or guardians) by telephone, 17 cases were reclassified as "false positive." These children, we determined, were not considered hyperactive by their physician, by their parents, or by the school system. Some of them clearly suffered from other behavior disorders but could not be considered as hyperactive. This reduced the number of potential interviewees to 212.

Three parents of these 212 could not be located to arrange interviews. Of the remaining 209 parents we had an 8.6% interview refusal rate. (Eighteen parents refused to be interviewed.) Of these 18 refusals, nine of the children had stimulant medication and had been terminated, four were in the monitoring phase and the remainder were either untreated or were not being treated by medication. The refusals were also well distributed among the schools in the sample. Four schools in the Grand Rapids system accounted for more than one refusal. The two schools that accounted for three refusals contained the largest percentage of hyperactive children in our sample of schools and thus the proportion of refusals found among parents of children in those schools could have been by chance.

Of the 191 parents interviewed, 6 parents (3%) refused to allow us to approach any other member of the set for additional interviews. Sixteen of the 191 parents interviewed, or 8.4%, refused us permission to allow to contact their child's teacher. Seventeen of the 191 parents, or 8.9%, refused us permission to contact their child's physician. The most numerous refusals were for permission to interview the child. Thirty-six parents, or 18.8% of the 191 parents interviewed refused us permission to interview their child.

In conducting the teacher interview the decision was made not to attempt to interview the teachers of hyperactive children whose course of medication had been discontinued more than two years prior to the beginning of the 1977 school year. It was thought that the logistics of locating the teacher, added to the uncertainties of retrospective data, would make this unproductive. Forty-nine children in our sample were "post termination (or second-order) stimulant medication children." Thus, no attempt was made to interview their teachers. One hundred and twenty-six teacher interviews were thus attempted. Of those, ten teachers could not be located: they had either left the school system or the geographic area or simply were not traceable. Of the 116 remaining teachers, nine teachers or 7.7% refused the interview. A total of 107 teachers were interviewed.

The physicians of 16 of the children in our sample whose parents had given us permission to interview the physician were not locatable. In several instances the physicians had moved but we were able to contact them and arrange an interview. One hundred and fifty-eight children's physicians, therefore, were approached for an interview. The physicians of 26 of those children refused to be interviewed. This, however, did not constitute 26 physicians, since a refusal by a single physician constituted a refusal for all the children in the sample that physician was treating. Of 79 physicians treating the children in our sample who were locatable, 13 or 16.5% refused to be interviewed. This accounted for 26 children or 14.9% of the children for whom parents gave permission to contact for their physician for a physician interview.

Of the 155 children whom we were given permission to interview, we were unable to interview four children. These were children who were either chronically absent from school (where the interviews were conducted) or whose parents had moved between the time that permission to interview them was secured and the interview itself was attempted. Of the remaining 151 children, two children or 1% refused to be interviewed.

Of the 191 sets for whom we had at least one interview, 51 or 27% were children who were not on stimulant medication or had never been on stimulant medication. These included those that had been treated with other sorts of medication (barbituates, major or minor tranquilizers, etc.), who had not received any medication at all for their condition, who had been diagnosed but not treated in any way, and the like. Of the remaining 140 cases, 12 or 8½% were in the initiation phase, 40 or 28.6% were in the monitoring phase and the remainder in the termination phase.

This configuration of interviews provided 72 "complete sets" consisting of parents, teacher and physician interviews. "Complete sets" yielded three dyads, parent/teacher, parent/physician, and teacher/physician. Sixty-five other sets consisted of two interviews. Sixteen of these 65 consisted of the parent/teacher interview and 49 consisted of the parent/physician interview. In each of these 65 sets one dyad, either parent/teacher or parent/physician was available for analysis.

The Kalamazoo sample of children and parents was derived from the 1978 Kalamazoo Live Y'er program described in Chapter Three. Forty-seven children attend the Live Y'ers program. Forty-three parents were interviewed. Four parents, or 9%, refused to be interviewed. Of the 43 interviews with parents completed, five parents refused permission to interview their children (11.6%). One child was not available for interviews because of other circumstances. Thirty-seven children were interviewed from the Kalamazoo Live Y'er program.

In the third chapter we commented on the enthusiasm with which parents greeted this research. At the outset of this undertaking, we were concerned that this sensitive topic would result in reluctance to be interviewed. Moreover, the subject requirements were such that the chances of losing interviews were increased by the necessity of having to receive permission to contact the interviewees, other than parents, and then receive permission from these interviewees. With the exception of physicians, for whom the refusal rates and the rates of refused consent to contact were somewhat higher than we had hoped for, the proportion of refusals were quite comparable to other studies. The refusal rates, usually 7 or 8%, seemed to us tolerable.

CHAPTER FIVE

PARENTS', TEACHERS' AND PHYSICIANS' PERCEPTIONS ABOUT THE DIAGNOSIS AND TREATMENT OF HYPERACTIVE CHILDREN

One of the major objectives of our research was the production of better descriptive information about the diagnosis and treatment of hyperactive children. Anecdotes and horror stories have frequently been used as the informational basis for evaluating the status of medication and recommending policy. Medical personnel have accused teachers of "prescribing." Teachers have decried the uncritical prescribing of stimulant drugs for their students. Physicians and teachers have noted that parents, on the basis of casual information, have pushed for the prescription of stimulants or have resisted or subverted the regimen.

We devoted a portion of the interviews with teachers, parents and physicians to obtaining the story of the treatment of the child from the perspective of these three key parties. In this chapter we will construct a description of the ways in which critical decisions were made and important events have transpired in the sequence of activities from the recognition of the problem to the termination of medical treatment.

As described in Chapter Three, we developed different interviews depending on the duration of time the child had been treated.*

Diagnosis and Initiation of Treatment

Our smallest group of subjects was that designated as initiation phase ($n = 12$). We augmented the information on the question pertaining to initiation by developing another set of data for a second group of subjects (Kalamazoo Live Y'ers). The data on the Live Y'ers group will be presented later in this chapter.

The first question to consider in the description of the diagnosis and treatment of children as hyperactive is: who recognizes the problem and how is it determined that the child is experiencing difficulties which go beyond the problems of children? Much of what emerges in the child's treatment may be shaped by the way the problem is recognized. The extent to which parents, teachers, and physicians function effectively in the first level of screening for problems of children is obviously critical to the ultimate success of the delivery of any helping services.

Teachers play an important part in the recognition of problems that lead to the diagnosis of children as hyperactive. Seven of 11 parents (64%), 6 of 12 teachers (50%), and 5 of 10

*All tables for this chapter are contained in Appendix J.

physicians (50%) said that the teacher was the first person or one of the first persons (i.e., teacher together with someone else) to recognize the child's problem and that this led to the diagnosis of hyperactivity.

The close agreement of the three samples with regard to the function of teachers in recognition of the problem is not mirrored in agreement about the parent role. Parents are reported to be the first or one of the first persons to recognize the child's problem by 3 of the 12* (25%) parents, 2 of the 12 (17%) teachers, and 8 of the 10 (80%) physicians. The differences in the physicians' perceptions may be a result of the tendency of physicians to come in contact with the problem through the parent. As a result, physicians may perceive the specification of the complaint by the parent as a recognition of the problem by the parent.

Of considerable interest is the fact that none of the respondents see the physician as the person who initially recognized the problem which led to the diagnosis. The condition is apparently not picked up by the physician in routine medical care of the child or when the child is being treated for other ailments.

In examining what parents, teachers, and physicians had to say about the nature of the problem that caused their concern, we find a variety of descriptions of the problem. Descriptive terms used were: "slow learner," "poor coordination of hands," "very violent," "irrational," "irresponsible," "problems getting along with other children," "short attention span," "not sitting still in the classroom," "emotional problems," "frustrated," "unhappy." These terms give an indication of the considerable range of behaviors that were identified in children by parents, teachers, and physicians which ultimately led to their being treated for hyperactivity. The most common concern on the part of parents was the problem of attention span and the child's high activity levels.

Another aspect of the reports of problems is the parents' sense of gravity of the situation. In some instances the parent indicated little difficulty at home but was informed of problems at school. In other instances parents reported that the child's behavior was extremely disruptive within the family unit. For example, one parent said, "He'd break things on purpose and I needed help. All of us. I'd get so upset, I'd just sit down and cry. I couldn't do nothing with him." There seems to be little pattern with regard to the agreement among parents, teachers, and physicians concerning the nature of the problem.

Not infrequently, there was quite a bit of difference among the three as to the nature of the child's problem. For example,

*N changes for the three groups because of missing data on particular questions.

in one case, the parent reports the problem as follows: "He was a slow learner, and had astigmatism, needed glasses, and poor coordination of his hands." The teacher reported for the same child, "Many behavior problems, not serious, just silly things, tried to get attention and make others laugh." And the physician, referring to the same child said, "The child was hyperactive, (had a) short attention span, wouldn't sit still." This contrasts with an instance where there is considerable agreement among the three samples. The parent said, "very violent, irrational, irresponsible." The teacher said, "family problems, defends himself with knife." The physician reported, "uncontrolled aggressive behavior." There appears to be a greater propensity for similarity of assessment of behavior in those instances where there are acute problems which have an episodic character. The variation in the description of the child's initial problem among the involved adults leads us to suspect that differences among responsible adults may originate in the very beginnings of the perceptions of the child's problem.

Another aspect of the teacher's participation at the early stage of problem identification is the involvement in the decision to seek medical help. Most of the teachers (9 of 11, or 82%) indicated that they took no part in the decision to seek help for the child. The majority of teachers in the initiation sample, 11 of 12 (92%), indicated that they did not make the decision to contact the physician. Only one teacher in the sample said that she was the first person to bring up the idea that the child needed help.

The children in our initiation sample, therefore, showed a pattern of having their problem first recognized by the teacher and having the subsequent steps for professional and medical help being initiated by their parent. Noteworthy is the fact that the social, behavior, and learning problems occasioned by hyperactivity are not picked up spontaneously by the physician. One further observation about problem recognition. The examination of the detailed table (Table 5.1, Appendix J) shows that few of the salient decisions occur through the concerted effort of parents and teachers and physicians.

One of the concerns that we had in examining the problems associated with the diagnosis of children was the extent of communication among the involved parties relative to the child's diagnosis. As might be expected, the parents report that they have had the diagnosis of the child's condition given to them by the physician in most cases (7 of 12). In three other cases the diagnosis came from the social workers or other professionals. Most teachers, however, were informed of the child's diagnosis by parents; various other sources, such as school psychologists, social workers, school nurse, etc., also provided the information to the teacher about the child's diagnosis. There is little direct communication between physicians and teachers about the child's diagnosis.

Another important aspect in communication is communication with the child about the details and meanings of his or her condition. Seven of the parents reported that they did discuss the meaning and details of the child's diagnosis with the child, four did not. Six of the teachers did so and six did not; five of the physicians did so, four did not; and one did not remember. Since the question as stated enabled us to collect an affirmative answer even if the discussion is of the most fleeting, ephemeral kind, we might have expected to see much higher percentages of response to this question. This response to this question suggests some thinness with regard to discussion between adults and children on the nature of the children's condition.

Since the way in which the child fares in the school system is not simply the function of any one teacher but is a consequence of the child's involvement with various teachers in the school, the issue of interschool communication relative to the child's condition is of interest. If the child's homeroom teacher is informed but other teachers and school personnel with whom the child will come in contact are not informed, it is conceivable that they will not have information which may be helpful to them in their interactions with the child. While one perspective is that the fewer the people who know about the child's condition, the better, the school system in which this study was conducted took the first posture and required that the information about a diagnosis of hyperactivity be recorded on school records. This was formal school policy; nevertheless, 10 of the 11 teachers reported that they did not provide this in the cumulative records. Since the data were not recorded by the end of the school year (April), we might conclude that the information would probably not get on the cumulative records. In addition, 5 of the 12 (42%) teachers reported that they did not communicate the child's medical diagnosis to others in the school system. Thus, we see that the prevailing posture is to provide for a limited amount of communication within the school system relative to the child's diagnosis. In the diagnosis of hyperactivity, communication within the school system and between school system members and physicians is largely a hit-and-miss, uncoordinated, phenomenon.

Medication Treatment

One of the most volatile aspects of the treatment of hyperactive children is the use of medication. In the popular literature on hyperactivity, it is often asserted that improper, unethical, or illegal acts occur in the decision to use medication. Thus, questions concerning the nature of the process for deciding about medication provides data that can be used to reexamine arguments of critics about the use of medication for hyperactive children. The extent to which the decision about medication use is made in a reasoned, careful way may go a long way toward determining the extent to which the child's treatment will have a positive consequence.

A minority of the parents (4 of 11, or 36%) reported recommending the use of medication. Of the four, two reported that they suggested a specific medication. An even smaller proportion of teachers (2 of 12, or 17%) reported recommending the use of medication, and of the two teachers who did recommend that medication be used, one of them reported suggesting a specific medication. Thus, from the reports of teachers and parents, to suggest a medication or even that medication be used in dealing with the child's problem is not a common approach.

One interpretation of these data is that the parents and teachers are not telling the truth. Teachers have been charged with bringing pressure on parents to seek medication treatment. The teachers in our sample all denied that they had recommended medication for the hyperactive children. When asked about this, two (18%) parents designated the teacher as a decision-maker in the use of medication and one of these two parents has the teacher as a joint decision-maker with the doctor and the parent. Both parents and teachers in roughly the same proportion (55%) designate the physician alone, or in combination with the parent or the teacher, as the decision-maker to use medication. Five of 11 (45%) of the parents indicate that they were the ones to make the decision to use the medication treatment; five of 12 (42%) of the teachers report that the parents were the decision-makers in the decision to use medication for the child.

In our interview we asked several questions about the parental discussions with others about medication. All parents reported having told the teacher that the child was being treated with medication. Since medication often is administered at lunchtime in school, involvement of the teacher is not infrequent. Thus, some measure of communication is probably inevitable when medication is used as a treatment approach. Also, all parents reported that they talked with the child about how medication would help.*

A good part of the concern about the treatment of hyperactive children with medication for children centers about the possible misuse of medication. When questioned, 8 of the 11 parents (73%) reported giving the child one or two pills to take to school each day. Eighty-two percent (9 of 11) of the parents reported that they personally gave the child a pill each time it is taken at home. In school, medication is stored in a variety of places.

*The critical question is, of course, how extensive are these discussions and what is being communicated? While we did not ask detailed questions about the nature of the discussion between parents and children, or between teachers and children about the nature of their condition or the nature or reasons for taking medication, we shall be able to examine the consequences of these discussions when we examine the data from the child interviews. This will tell us what the child understands about the nature of his or her condition and the medication that is being provided for it.

Some of the medication is kept in the child's classroom or the school office, some in the nurse's office. In some cases (2 of 11), the child keeps it with him. Twenty-seven percent of the teachers (3 of 11) report they do not know where the medication for the hyperactive children in their charge is kept at school.

The circumstances under which changes in the medication regimen were made was also investigated in the research. Forty-two percent of the parents (5 of 12) report that they changed the dosage or the time when the child takes his or her medication depending upon their perceived needs. One of the teachers when questioned about this, reported doing it.

Monitoring the Hyperactive Child

The monitoring group was comprised of interviews with 42 parents, 37 teachers and 37 physicians. Federal law requires the monitoring of children being treated with stimulant medication (medication can only be provided for a thirty-day duration; therefore, monitoring is required for children who are taking medication on a continuing basis). In our interview we asked a series of questions about monitoring.

One of the questions in this section of the interview dealt with the regularity of medical check-ups. When we compare the responses of parents and physicians, we find that there was a tendency for parents to report more frequent visits to the physician than were reported by the physicians. Twenty-three of the 42 parents (56%) reported going to the doctor more than once a year. Thirty-three percent (10 of 30) of the doctors reported that their patients came to them more than once a year for monitoring. The distribution of reported visits (see Table 5.2, Appendix J) shows this discrepancy between parental and physician reporting in detail.

A similar difference is noted when we asked parent and physician who takes responsibility for the medical monitoring of the child via scheduling check-ups by a physician. Sixty-five percent of the physicians (17 of 37) say that they are responsible for and do schedule such periodic examinations. Sixty-three percent of the parents (26 of 41), however, say they take such responsibility - either through requesting a prescription refill or scheduling visits when the parent thinks it is necessary. With regard to the monitoring of the hyperactive child receiving medication, parent and physician have different views of what is going on. Their disagreements are substantial. It is important to note that two-thirds (20 of 30) of the physicians reported that the visits with the child for a check-up for medication occurred once a year or less frequently.

With regard to the frequency of parent-teacher conferences, we find that there is a tendency for teachers and parents of

hyperactive children to meet with greater frequency than is reported for other children in the class. Teachers report the norm for meeting with parents of children in their class is two times per year. (Sixty percent, 20 of 33, of the teachers reported that they meet with parents twice in one year.) For parents of hyperactive children, however, the frequency of meetings is greater. Only 37% of the parents (15 of 41) report meetings of two or fewer times with teachers. The mean number of meetings reported by parents is 3.2 per year. The teachers report that they met with parents on the average of 4.9 times per year. One consequence for teachers of having hyperactive children in their classroom is the increased amount of time and energy which is spent in parent/teacher conferences.

A critical aspect of the monitoring of a child's regimen is the evaluation of the effectiveness of medication treatment. We asked parents, teachers, and physicians about their activities in monitoring the side effects, the dosage adjustment and the efficacy of the medication treatment children were getting. Nearly all physicians reported that they received information from either parent or teacher to help them decide if the medication has resulted in harmful side effects (94%, 29 of 31). Eighty-eight percent of the parents (36 of 41) reported providing the physician with this information, but only 19% (7 of 36) of the teachers interviewed maintained that they had ever provided this information. The information provided about the side effects evident in school is transmitted to the physician via the parent. This observation is buttressed by the fact that 76% (31 of 41) of the parents indicate that they serve as a channel of information during this monitoring process between teacher and physician.

The data on dosage level is similar. Virtually all physicians (over 90%) report getting information from parents and teachers. Eighty-three percent (34 of 41) of the parents report giving such information but only 17% (6 of 35) of the teachers report giving this information to the doctor directly.

Another important problem is the relationship between teacher and physician in the effect of the child's medication treatment on school performance. As previously noted, a great deal of the hyperactive child's difficulty occurs in school and with schoolwork. The majority of children, being treated with stimulant medication, notably Ritalin, take their medication in school for this purpose. When asked whether the teacher provides information directly to the physician in order to evaluate the efficacy of the medication treatment, 19% (7 of 36) of the teachers said they did. The physicians' perception of this communication is considerably different. Fifty percent (16 of 32) of the physicians said they had received information directly from the teacher. Of the 16 physicians who indicated that they received direct information, however, only two reported that they received written information of any kind.

Finally, we were concerned with the attempts of parents or teachers to suggest that medication be suspended in the case of children in their care on a trial basis, or the request of the parent or teacher that medication be ended. Thirty-one percent of the parents (13 of 42) report suggesting to the physician a trial discontinuation of the medication and 14% of the teachers (5 of 37) suggested that the medication be discontinued on a trial basis for their students.

Adjunctive Therapy

The literature on hyperactive children stresses the importance of adjunctive therapy. Even promotional literature provided by manufacturers of the commonly used medications indicates that the medication by itself is not sufficient to remedy the problems that the child is experiencing. It makes both common and medical sense to understand that the medication by itself cannot correct many of the important educational, behavioral problems that have led the parents to seek help for their child. It was for this reason that we included a section during the interviews to examine the extent and nature of adjunctive therapy.

The most striking finding (see Table 5.3, Appendix J) is the paucity of other approaches which would either supplement the medication or begin to deal with the more fundamental problems involved in the child's treatment. Treatments such as megavitamin treatment, special diet, psychiatric, special education, counseling and behavioral modification are employed quite infrequently.

It is also of interest that the reports across samples are fairly consistent. There are no large differences among the parents, teachers, and physicians as to the extensiveness of these treatments. It is perhaps of even greater concern that some of the treatments which are more easily claimed are in no instance reported for more than 50% of the children, i.e., "changes in the manner of relating to the child." The benefits that may accrue from the medication can provide the basis for insuring the success of these changes. These data, thus, point fairly clearly to an important consideration relative to the treatment of hyperactive children: the use of medication tends to be perceived as a more complete, omnibus solution to the child's problem than the medical or educational literature would seem to warrant.

Social Psychological Context

The literature on hyperactivity has paid special attention to problems of stereotyping and stigmatizing the children. Diagnosis of the children as hyperactive and their treatment with medication could be an additional problem for them. If the children are teased because they are hyperactive or because they are taking medication, if they are treated unfairly, or if they have

bad feelings about their diagnosis or treatment, it could disrupt the effectiveness of the treatment.

We inquired about these kinds of considerations in our interviews and generally found a few reports on the part of parents, teachers and physicians that there were negative psychological or social conditions in the life of the child. The majority of parents, teachers and physicians indicated: (1) the child had not been treated unfairly because of his or her diagnosis; (2) the child's chance for success in school would not have been better if school personnel did not know of the diagnosis; (3) the child did benefit at school because other personnel knew of his or her diagnosis and treatment as hyperactive; (4) the child had not been teased at home because of his or her treatment; and (5) the child had not been teased at school because of treatment.

While it would be inappropriate to define any of these problems as being generally the case for the hyperactive children we studied, there was some evidence that problems related to the stereotyping, stigmatizing, and other adverse psychological conditions did exist for some children. Physicians tended to report these problems less frequently than teachers who reported them less frequently than did parents. This is quite reasonable given the differences in contact with the child. The most frequently cited problem was that the child was teased at school because of his or her condition. Thirty-one percent (54 of 177) of the parents reported that the child had been teased in school.

Our data point to a phenomenon that we have observed in other situations which we might characterize as the "proximity - sensitivity relationship." When we examine the question of differences between parental attitudes toward treatment, we find that there is a greater inclination for the mothers to be favorable to the treatment than fathers. In other research we have seen a tendency for practicing teachers to be more positive toward treatment than prospective teachers and for superintendents to be less favorable than teachers (Robin and Bosco, 1974). Since mothers generally spend more time with the children, it is quite likely that the more favorable attitude is a consequence of their own more extensive interaction with the child's problems prior to treatment and with the alleviation of the problems after treatment. Perhaps fathers, who are generally in less contact with the child, have a greater propensity to consider the ethical, moral, and philosophic aspects than do mothers who are more frequently confronted with the reality of the behavior.

In summary, what these data indicate is that parents, teachers, and physicians generally report a positive psychological and social environment. It must be remembered that the samples we are using are not general population samples but, rather, those who have accepted treatment or are part of a treatment program. It would be erroneous to generalize these attitudes to a general population.

Assessment of Parents, Teachers, and Physicians about Severity of Condition Prior to Treatment

The natural history and social context of hyperactive children, the agreement and disagreement among adult populations about the course of treatment and what has happened and should be done with such children, may hinge upon the severity of the condition and the agreement among the sample about that severity. Previously, we have discussed that parents, teachers and physicians, each belonging to separate social systems with different perspectives, may very well see the child and the disorder of the child in a different light. In this section, we examine the assessment by the parents, teachers, and physicians about the severity of the condition of our sample of children.

Parents, teachers, and physicians all saw the children in our sample as having considerable or severe problems prior to treatment. Modal categories for parents and physicians were "considerable problems" and for teachers, "severe problems." The majority of parents, teachers, and physicians saw the child as having considerable or severe or even most severe problems. More physicians tended to see the children as having only mild or moderate, or borderline, problems than did the teachers. More teachers in turn saw the children as having borderline, mild or moderate problems than did parents, but all agreed that the majority of the children had more severe problems. A very small proportion of all three samples assessed their children, their students, and their patients as having no or only borderline problems. While there were a few parents, teachers, and physicians who maintained that the children had no problems or only a borderline problem, the important finding is that the majority agreed that the children had considerable or greater problems.

Assessment of Parents, Teachers, and Physicians of a Change in Child's Condition since Medication Began

No less essential to understanding the natural history of hyperactivity, its diagnosis and treatment, or its severity, is the assessment of the adults about the success of the medication treatment. The agreement among the three samples about the change in the child's condition is strong. For all three samples, the modal category is "much improved" - the second highest category available to our respondents. A majority of parents, teachers, and physicians say that the child is either "very much improved" or "much improved." Teachers tend to be a little more conservative than parents or physicians in their assessment of the child's improvement, and parents are the only respondents who categorize any of the children as being "worse," "much worse," or "very much worse" since the beginning of the treatment. Essentially, however, parents, teachers, and physicians see the child as getting better since treatment and agree among themselves to the extent to which that is so when the sample is considered as a whole.

Assessment of Parents, Teachers, and Physicians about Side-Effects of Medication

There are sharp differences among physicians, parents, and teachers in their estimates of the severity of side-effects of medication treatment. Physicians tend to report the least amount of severe side-effects of medication treatment (87%, 80 of 115, of the physicians said there were no side-effects). Of the three groups, parents reported side-effects with the greatest frequency. Still, 58% (97 of 167) reported no side-effects. Teachers fall in between with a percentage of 70% (52 of 80). Parents, teachers, and physicians were all quite comparable in their reporting of moderate side-effects. However, there were considerable differences among parents and teachers and physicians. Parents and teachers reported more severe and more serious side-effects than did the physicians, and parents somewhat more than teachers. It is understandable that parents would be somewhat more aware of the side-effects than would teachers since some of the side-effects, such as sleeplessness, interruption, or changes in eating habits may be more conspicuous to parents than to teachers. It is somewhat surprising, however, that the individuals who monitor the side-effects, the physicians, tender the fewest reports of side-effects. There is clearly disagreement among the three groups as to the extensiveness of severe side-effects. Some of this may be interpreted in the obvious differences and standards of what constitutes a severe side-effect. The differences among teachers and parents, therefore, in the perception of the presence or absence of side-effects may be either because parents do not tell physicians about their perceptions or the physicians do not credit the parent's account as being accurate or sufficiently important to enter into the child's records. Even if one believes that the differences are accounted for by the difference in standards for judging what constitutes a severe side-effect, these data point to the fact that the communication between physicians and parents is faulty in evaluating the success of the drug regimens.

Termination of Treatment

There is no segment of treatment which appears to be as unplanned and as happenstance as the termination of treatment. One might conceive of the termination of treatment as being the logical and explicitly anticipated conclusion of a sequence of actions that have ensued from the initial decision to treat. An examination of the data from parents, teachers, and physicians on this stage of the process indicates an ending without a conclusion. Our subject groups for these interviews were 113 parents, 31 teachers, and 68 physicians.

For the most part, the decision to end medication treatment seems to be made most frequently by the parent, less frequently by the physician. In 20% (6 of 30) of the cases, the teachers reported that it was at their suggestion that medication treatment be terminated.

Termination of treatment is typically not a planned phase in the process. Very few physicians (3 of 53, or 6%) made any special plans for terminating medication. A somewhat larger percentage of parents, about one-third of them, indicated that they did make special plans for the termination of the child's medication. Half of the parents and physicians reported that they tried a trial discontinuation of the medication to see the consequences of ending treatment.

Consistent with the finding relative to the monitoring of treatment, physicians report little contact with teachers relative to the termination of medication. Two-thirds of the physicians (37 of 54) reported that they did not collect information from the teacher. Half of the parents, however, did report collecting information from teachers.

Physicians generally did not decide to end the treatment guided by a physical examination of the child. Three-fourths of the physicians, (36 of 49) report that they did not provide a physical examination at the termination of treatment. In instances where there is a clear organic pathology it is to be expected that an examination would be useful to determine whether the treatment has been effective. If the condition is more elusive and less likely to be diagnosed using an examination, then we should expect an accordingly low usage of any examination in order to determine if the treatment should be terminated. This seems to be the case with hyperactivity.

With regard to post-treatment aspects, by and large, 3 of 41 physicians provided parents with information about ways of disposing of medication when the treatment was ended. Since the stimulant medications are considered to be a type of psychoactive chemicals which can be abused it would seem reasonable for physicians to inquire about the amount of pills that were left over and to provide clear and adequate information about the ways to dispose of those which were remaining. In several instances, as we conducted interviews, we realized that while the parent had ended the treatment this had not been communicated to the physician and had not been communicated to anyone until our interview took place. In other instances, the physician assumed the child had discontinued medication only because as he checked records during the interview it was clear that the prescription had not been refilled. Clearly, in these cases, the physician's ability to advise the parent about post-medication treatment of the child, disposal of unused medication, and similar matters, is severely limited.

The picture that emerges from this section of the interview is the termination of treatment as a relatively spontaneous and undeliberate aspect of the process. It typically does not entail high degrees of structure nor any extensive interaction among the participants in the process. Treatment for children just seems to fade away rather than end with any careful consideration of

subsequent procedures or processes that are useful to the maintenance of the child's health or education.

CHAPTER SIX

BELIEFS ABOUT AND ATTITUDES TOWARD HYPERACTIVITY AND ITS TREATMENT WITH STIMULANT MEDICATION

Earlier in this report the question of systematic difference in perception, belief, and attitude among members of the three social systems dealing with hyperactive children was discussed. In this chapter we present data concerning the beliefs about and attitudes toward the nature of hyperactivity and its treatment as held by parents, teachers, and physicians. This is done via a scale developed to measure general attitudes toward medication for hyperactive children. We then examined specific attitude items that were asked of parents, teachers, and physicians, some of which comprised the scale. Finally, we examined the beliefs about hyperactivity: its nature and its origin, as held by these three groups in the children's lives.

General Attitude toward Medication for Hyperactive Children

Parents, teachers, and physicians all hold generally favorable attitudes toward the treatment of hyperactive children with medication. Very few are strongly opposed to the use of medication. In each of the three groups, three-quarters of our respondents are in favor of the use of medication for hyperactive children. (See Table 6.1, Appendix K.) The major difference among the groups is that physicians are more strongly in favor of medication for hyperactive children than are either of the other two groups. Over half of the physicians fall in the most favorable scale score attitude group concerning the use of medication. Less than one-fourth of the teachers and physicians and parents have scale scores in that most favorable category. As groups, the parents and the teachers present very similar pictures on the Guttman Scale. The physicians are considerably stronger in their endorsement of medication.

We have also analyzed each group separately by the three phases of treatment. (See Table 6.2, Appendix K.) There is not a great deal of variability among the three treatment phases for any of the three samples. Parents, teachers, and physicians all tend to be strongly in favor of the use of medication for hyperactive children no matter which phase of treatment the child in their care happens to be in. Examination of the differences in attitudes toward medication use by hyperactive children by phase of treatment within each sample indicates no significant differences for any of the samples across the phases. In each sample there is some slight variation in the proportion favorable, but these differences are not significant.

The distribution of the Kalamazoo sample on the Guttman Scale, measuring the general attitude toward medication for hyperactive

children, is very similar to that of the Grand Rapids parental sample. The Kalamazoo parents were slightly more in favor of medication for hyperactive children. None of the parents had scale scores in the category of greatest opposition to the use of medication for hyperactive children. Slightly higher proportions (on the order of 5-9%) were in the second and third most favorable categories. (See Table 6.3, in Appendix K.)

Item Examination of General Attitudes of Parents, Teachers, and Physicians

A somewhat different picture emerges when the individual items of the general attitude scale are examined. Approximately 95% of the parents, teachers, and physicians agree that "medication is not the total solution for the hyperactive child, but it is a useful and important part of the solution." Fifty-six percent of parents and teachers agree with the statement that "while the use of medication may be necessary for a small percentage of children, its use has become too widespread." More physicians than parents and teachers agreed with this statement (34 of 51, or 68%). The physicians are more critical of the current usage of medication for hyperactivity than either the parents or the teachers.

Two-thirds of all parents and teachers agree that "there is so much confusion about what hyperactivity is, that the use of the medication is questionable." Less than 40% of the physicians agreed to this item. Fifty percent of teachers and 60% of physicians agree that "most doctors are careful in prescribing medication and they work well for hyperactive children." Far more, almost 80% of the parents expressed this belief in the carefulness of the prescribing physician. Whether this greater trust in physicians on the part of parents is reflective of the naivety of the "non-expert" or whether it reflects the reality of living with a child for whom such medication has been prescribed is not known.

When questioned about agreement with the statement "Not enough is known about the dangers of medication to make it a safe approach," the three samples responded in much the same fashion that they did to the item concerning confusion about hyperactivity making the use of medication questionable. Although a smaller proportion of each sample agreed to this than to the former question, nearly 50% of the parents expressed doubt about the state of knowledge of the dangers of medication, as compared to only one-third of the teachers, and less than one-fourth of the physicians. The physicians in particular tend to minimize the dangers in the use of medication for hyperactivity while the other groups are not quite as sanguine.

Two items were constructed to elicit, from the groups, responses to extreme statements, positive and negative, about the

use of medication for hyperactive children. One item: "it is never proper to use medication to tamper with the minds of children in school" evokes very different responses from the three samples. In none of the samples did a majority of our respondents agree to this item. However, over 35% of the parents agreed with this statement, contrasted with just a little over one-fifth of the teachers, and one-tenth of the physicians. When the groups were asked to respond to the item "it's a shame to let children suffer when there are medicines like these that can help them," each of the samples overwhelmingly agreed with this item. Ninety percent of the parents, and approximately 80% of the physicians and teachers agreed with this statement. These groups, then, were quite different in the extent of their rejection of the negative end of the belief continuum, but agreed on their endorsement of the positive position.

Examination of the constituent parts of what we measured as a general attitude toward the use of medication for hyperactivity shows that, even though these items scaled as unidimensional by Guttman standards, there is considerable variation in the component belief by sample. As with the general attitude score, parents and teachers tend to agree with one another more than either agrees with physicians. Physicians tend to be more positive on items that call for more specialized knowledge. And parents seem to feel more strongly about items which call broader, ideological, or ethical questions into play.

Fewer Kalamazoo than Grand Rapids parents (slightly more than two-fifths) agreed that the use of medication has become too widespread. Grand Rapids and Kalamazoo parents agreed very closely, more than three-quarters of each sample, that physicians are careful in prescribing medication. The two samples agreed quite closely, over two-thirds, that the use of medication may be questionable because of confusion over the nature of hyperactivity. Somewhat more Grand Rapids parents, about 46%, feel that not enough is known about the dangers of medication to make it a safe approach than do Kalamazoo parents, 35%. Similarly, more Grand Rapids parents, about 36%, as compared with just over one-fifth of the Kalamazoo parents, agreed that it is never proper to use medication to tamper with the minds of children in school. Almost all of the Kalamazoo parents (all but one) believed that for children who need them, medicines for treatment of hyperactivity are almost a miracle. This compares with four-fifths of the Grand Rapids sample who felt the same way. A vast majority, 90% of the Grand Rapids parents, and all but one of the Kalamazoo parents, thought that it's a shame to let children suffer when there are medicines like these that can help them. The same proportion of Kalamazoo and Grand Rapids parents thought that medication was not the total solution but a useful and important part of the solution.

It is important to note the strong convergence of opinion between these two samples - samples that differed in the manner

in which they were selected. The generalizations made above about the Grand Rapids sample, the major parental sample in this research, can be extended without difficulty to the Kalamazoo sample, and the general attitude about medication is therefore homogeneous among the two major sets of parents in this research.

Attitudes of Parents, Teachers, and Physicians toward the Use of Medication for Children in Their Care

In addition to questions about the use of medication for hyperactive children in general, we examined the attitudes of parents, teachers, and physicians concerning the use of medication for the child, the student, the patient, in their care. Literature previously cited indicates that endorsement of psychoactive medication in general populations increases when the respondent is concerned with a situational or personal circumstance as opposed to an abstract, general circumstance. In addition, our sample is comprised of the parents, teachers, and physicians of children for whom medication has been prescribed, and/or who, for some period of time, have been taking medication. Negative attitudes toward medication for these children may indicate that the responsible adult thought that an error had been made in the prescription and the taking of the medication.

When comparing the attitudes of parents, teachers, and physicians toward the use of medication for children in their care (see Table 6.4, Appendix K), we note that, unlike the expression of attitudes in general, there is a convergence between the feelings of physicians and parents, while teachers are markedly different from both of the other groups. For parents and physicians, more than two-fifths of each sample elected the positive, unambivalent statement about medication and their child, "I strongly favor the treatment of this child with medication." These responses were the model responses for both parents and physicians. Just over one-quarter of the teachers agreed with this statement. Almost one-third of the parents and physicians chose the item which read "I have some misgivings about the use of medication but am inclined to favor it for this child." Close to two-fifths of the teachers selected this item. The comparable ambivalent item which leaned toward a negative position, "While I see something in its favor, I am inclined to disfavor it for this child," was selected by approximately one-fifth of the parents, and almost one-quarter of the physicians. Only 16% of the teachers selected this category. The unambiguous disapproval of medication for the child was indicated by 6% and 8% of parents and teachers respectively, but by none of the physicians.

The salient findings about this attitude are the much greater ambivalence of teachers about medication for the children in their care, and the relatively low, unqualified endorsement given by all three samples talking about children in their care who have been on, or are currently on, a medication regimen. For example,

almost half of the parents, over half of the teachers, and half of the physicians selected an ambivalent attitudinal response. Qualifications, whether leading to a positive or negative assessment, occur for most of the respondents in each sample. Even if there are some differences among the three samples, none of the three samples displayed the overwhelming (indeed mindless) endorsement of medicating the children in their care that has often been portrayed in the media.

Kalamazoo Sample - Attitudes toward Medication for Children in Their Care

The Kalamazoo group of parents displayed somewhat different attitudes toward medication for their children than did the Grand Rapids sample. One-third of the sample endorsed the medication without qualification, while 55% of the sample are ambivalent, leaning toward favoring its use for their child. Virtually all responses were in these two favorable categories. The ambivalence noted in the three samples in Grand Rapids is also to be found in the Kalamazoo parent sample. The positive ambivalent category is the model category for the Kalamazoo parent response. The general attitudes of Kalamazoo parents of hyperactive children are quite similar to those of Grand Rapids parents though slightly more favorable.

The Beliefs of Parents, Teachers, and Physicians about Hyperactivity and Its Etiology

Of considerable importance to the coherence of the child's environment and the ability of parents, teachers, and physicians to communicate and work in organized fashion in the diagnosis and treatment of the hyperactive child is the convergence of their beliefs about hyperactivity. There are many different views on the nature and etiology of hyperactivity in the popular and technical literature. Parents, teachers, and physicians may secure information about hyperactivity from university training, in-service training, discussion, magazines, television, newspapers, and the like. Whatever the sources of information, the convergence of the members of the three social systems and their views about this disorder is of considerable importance to the child, and his treatment.

We will first examine the general beliefs about hyperactivity. When asked to respond to the statement: "the term hyperactive is used to characterize children who are energetic, active, creative, or merely restless," a majority of each sample tended to agree. Just over half of the physicians and teachers agreed with that statement, but over 70% of the parents agreed. (See Table 6.5, Appendix K.) More of the parents, therefore, tended to view the label, hyperactive, with some benign denotation. The more personal involvement with the hyperactive child on the part of the

parent may well serve as motivation for this view. A sharp reversal of these beliefs was seen when the three groups were responding to the statement: "In some instances it may be a good thing for a child to be hyperactive." Over half of the physicians and teachers agreed to that statement, but only 32% of the parents agreed with the statement. Appreciable proportions of the physicians, parents, and teachers agreed with the statement that: "The term hyperactive is used by people to make it possible to control or to suppress children." In each group the plurality agreed (43% for parents, 44% for teachers, and 54% for physicians).

We asked respondents whether the term hyperactive is a legitimate diagnosis of a real problem for some children. Overwhelmingly, parents (93% of them) agreed that it was. Almost as many teachers agreed, but only three-quarters of the physicians agreed to this statement. In the realm of medical diagnosis and medical entity, therefore, the physicians show the least amount of agreement among the three samples.

The meaning of the samples' responses to these four items characterizing hyperactivity is that they agree that hyperactivity is a real problem and a real medical entity. When asked specific questions, each of the samples has a large proportion qualifying the pathological implications of the label hyperactive. In three of these four items, the samples respond in manners differing significantly from one another. The perception of hyperactivity among parents, teachers, and physicians is not homogeneous. They differ from one another in what they believe the label is and means.*

When examining the parents', teachers', and physicians' notions about the etiology of hyperactivity, we also note considerable difference among the three samples. Of the six questions

*One of the things that caught our eye was that 26% of the physicians (13) said that they disagreed with the statement: "The term 'hyperactive' is a legitimate diagnosis of a real problem for some children." We reviewed the tapes of the interviews with those physicians, to audit their response to this item. One physician said, "I don't know if it's a legitimate diagnosis. I'd have to say hyperactive is - I don't like to call it a diagnosis I guess." Other physicians refer to hyperactivity as a syndrome or a description rather than a diagnosis, buttressing our concern that the argument was with terminology rather than with medical entity. One disagreeing physician said "No. It's just a symptom, not a diagnosis." Another comment was: "I think it should be the hyperactive child syndrome. Just to say a child is hyperactive without the syndrome, there is no point. If you're just saying he is hyperactive that's not a diagnosis." Another physician noted, "I wouldn't call it hyperactive, so I would say no - because I just use the word syndrome."

asked about etiology, there were significant differences among the three samples on four of these questions. On two questions, "at least some cases of hyperactivity are caused by psychological or emotional problems" and "at least some cases of hyperactivity are caused by lead poisoning" there were no differences among the samples. Overwhelming proportions of all three samples agreed that cases of hyperactivity are caused by psychological or emotional problems. Close to, or over 90% of each of the samples agreed to this. In the case of lead poisoning being a cause of hyperactivity, large proportions of both samples simply said they did not know. These ranged from about one-quarter of the physician sample to 70% and 90% of parents and teachers respectively. Of particular interest here, however, are the responses of the physicians. Fifty percent of the physicians agreed that lead poisoning could cause hyperactivity. The other 50% were divided equally between disagreeing and not knowing.

Teachers and physicians agree in proportions far greater than parents that some cases of hyperactivity are caused by physiological or neurological disorders. Three-quarters of the parents agreed that this may be the case, but greater proportions of teachers (88%) and physicians (92%) agree. This may reflect the tendency on the part of some parents to deny either the reality or the physical reality of their child's disorder. Parents also agreed less than teachers and physicians that some cases of hyperactivity are caused by poor nutrition. A majority of the teachers and over two-fifths of the physicians agreed with this statement, but only 37% of the parents did.

Even more dramatic, and in the same direction, is the distribution of opinion about poor social conditions as a cause of hyperactivity. One-third of the parents denied poor social conditions as a basis for hyperactivity as opposed to one-fifth of the physicians and less than one-tenth of the teachers. Over three-quarters of the physicians felt that the etiology of hyperactivity could be tied to poor social conditions. More than two-thirds of the teachers felt this way, but just over two-fifths of the parents felt this was a possibility. Finally, continuing the pattern, more physicians and teachers felt that poor schools could be a cause of hyperactivity than did parents. About half of the teachers and physicians felt that this might be the cause, compared with just over one-third of the parents. Half of the parents disagreed that this might be a cause, compared with just over one-third of the teachers and two-fifths of the physicians. It is interesting to note the strong proclivity of the teachers to ascribe causality of hyperactivity to bad schools. More teachers agreed that bad schools might be the cause of hyperactivity than either the parents or the physicians.

When asked whether food additives might be a cause of hyperactivity, the physicians were least likely of the three samples to credit this as a cause. Less than one-fourth of the physicians thought that this was a possible cause, compared with two-thirds

of the teachers and almost two-fifths of the parents. Over half of the physicians indicated that they did not know, and slightly over half of the parents were uncertain.

These data show a difference in opinion about the etiology of hyperactivity. Physicians, no less than teachers and parents, show themselves divided over other possible explanations such as social conditions, food additives, schools, and lead poisoning. Parents manifest different belief patterns than the physicians. The difference between parents, teachers, and physicians about the etiology is striking.

Summary

The data support the positing of systematic differences in perception, belief, and attitude among the parents, teachers, and physicians responsible for the hyperactive children in our sample. The differences among the three groups seem to reflect the previously discussed differences among their social systems. Those differences, it was predicted, would generate among system members systematically different perspectives on hyperactivity and its treatment.

The differences among involved system members, in turn, were seen to produce not only a lack of articulation among the system in general but an incoherence in the hyperactive child's environment in particular. The reaction to hyperactivity creates an environment which is unpredictable for the child. The incoherence of the child's environment, resulting from the differing beliefs and perspectives on the part of the significant adults in his environment, provides yet another source of difficulty for the hyperactive child. There is a double penalty: the social difficulties under which the child is laboring are increased and these difficulties are organized around attempts to deal with the child's condition.

CHAPTER SEVEN

THE CHILDREN: THEIR ATTITUDES, PERCEPTIONS AND EXPERIENCES

No issue pertaining to the use of stimulant medication is more important than the consequence of stimulant medication on the children being treated. There has been much research about the effect of medication on various scholastic and cognitive variables, and there has been some speculation (and assumptions) about the consequences of stimulant medication on attitudes and other kinds of perceptions formed by the child. When we began this research, we could find no research on the impact of medication treatment on hyperactive children from the perspective of the children. Information about the perceptions, beliefs and attitudes of the children themselves was lacking. This struck us as a particularly critical gap in knowledge of the social, psychological, and educational effects of the diagnosis and treatment of hyperactive children. Although parents, teachers and physicians intersect the hyperactive child's life most significantly, it is the reaction of the child that is the product of continuous, intimate living with the problem. Ultimately the reactions of the child are the gauge of the impact of this condition upon the child and the success or failure of the treatment.

One of the problems we encountered, as we made plans to interview the children, was the extent of their awareness of the diagnosis and treatment. Some of our consultants told us that we ought not to expect that hyperactive children would make good research subjects. We were cautioned to be modest in our expectations of our interviews with children. Not only, we were told, would we have the problem of interviewing young children but, in addition, we would encounter the problem of interviewing hyperactive children, who would be particularly non-reflective and oblivious to those aspects of their environment pertaining to their diagnosis and treatment.

Thus, it was with some trepidation that we began the interviews with children. We were uncertain about how much information we could obtain from the interviews; we were even more concerned about the potential for trauma from the interviews. If, indeed, the children were oblivious and unmindful of their diagnosis and treatment, an interview which focused questions on these concerns could potentially raise new and additional issues and problems for the children. Both for reasons of avoiding trauma and testing how accurately the extent of the children's obliviousness had been predicted, we began the interviews with a series of questions that examined the extent of their awareness to their diagnosis and medication treatment.

We found that most children were aware of their diagnosis as hyperactive. When we asked questions about the knowledge about

the medication that was taken to help them in school or at home, most of the children in both the Grand Rapids and Kalamazoo samples demonstrated awareness (83% in Grand Rapids [108 of 130] and 94% in Kalamazoo [34 of 34]). When asked why the medication and pills were being taken, the most common responses were "because I am hyperactive" or "to calm me down," or some variation on responses such as these.

Our interviewers were carefully trained to ask the open-ended questions, to listen to the responses made by the children, and to watch their reactions to the questions in order to determine whether the issues and questions that were being presented to them were uncomfortable or unfamiliar ones. If they perceived this to be the case, they were instructed to skip the rest of the questions that pertained to the diagnosis and treatment and to end the interview with the self-esteem scale. This procedure was only required in 17% of the cases in Grand Rapids and 3% in Kalamazoo. Our interviewers were also trained to assess the extent to which it appeared the child understands the role of medication in the treatment of his condition. A substantial percentage of both samples (68% in Grand Rapids and 79% in Kalamazoo) were judged understanding of the medication and the use to which it was being put. (See Table 7.1, Appendix L.) The conclusion this leads us to is that children in both samples were generally cognizant of their condition and had linked the use of medication to that condition. This is particularly impressive since 40% of the children (36% in Grand Rapids, 53% in Kalamazoo) reported remembering no communication explaining the medication (see Table 7.2, Appendix L).

As might be expected, given the variety of positions which exist on the part of parents, teachers, and physicians concerning the function of the medication, there was variation among children about the reason for the medication but, to a considerable extent, the children in both samples demonstrated that they were not oblivious to their status as a diagnosed hyperactive child, that they did perceive themselves as having a behavioral or learning problem, and that the medication they were taking was in some way intended to help them with that condition.

Even though most children were aware of their diagnosis and treatment, there was much murkiness about how and why treatment began. Doubtless, some of this murkiness was caused by the time which had elapsed from the commencement of the medication treatment to the time of the interviews. About half of each sample of children could not recall a critical incident that led to the decision to medicate (Table 7.3, Appendix L). About a third of the children cited problems in school or learning or behavioral problems as a critical incident. This indicates that the child's perception of the problem does not appear generally to be linked to a crisis. When it is linked to a crisis, the school is the site of the incident.

Along the same lines, even though some of the literature (particularly the popular literature) attributes the use of medication to teachers, the children in our sample tend not to see teachers as involved in the decision to initiate medication. The perception of the children is more convergent with the perception of the adults in their environment that the decision to begin medication lies within the domain of physicians and parents.

Eighty-six percent of the children in our samples reported that their physicians or parents initiated the idea of medication. About half the children in both samples reported the physician as initiator; slightly more than one-third (38% in Grand Rapids, 24% in Kalamazoo) cited their parents as medication initiators. (See Table 7.4, Appendix L.) Only 6% of our Grand Rapids sample and 3% of the Kalamazoo sample report that the teacher was the decisive person in the decision to begin medication. Three children in our Grand Rapids sample indicated that the decision to begin medication was made by themselves.

One of the focal points of the interviews with children was their perception of the communication of parents, doctors, and teachers with them. During the parent, teacher, and physician interviews, we asked a number of questions about communication with the child. We also asked these questions of the children themselves. Thirty-seven percent of the Grand Rapids children and 56% of the Kalamazoo children indicated that there were no conversations with them. We find this a particularly troublesome finding. Even if the conversations did occur with some children who did not report them, the usefulness of those conversations is in considerable measure reflected in the recollection of them. However, it is not inconceivable that conversations may have been very beneficial and had an impact on the child's life even though they are no longer remembered.

About two-thirds of the Grand Rapids sample and one-half of the Kalamazoo sample reported conversations with people who explained the medication to the child. When these conversations occurred, they typically occurred with the doctor (21%) or the parent (44%). In only one instance, in both samples combined, was there a report of a conversation with a teacher pertaining to the medication treatment. (See Table 7.2, Appendix L.)

The children generally perceived the nature of the medication to be tied to the need to calm or slow them down, to treat their hyperactive condition, to assist them with school work or because of misbehavior. The first two of these explanations were provided by roughly one-third of the children and the second two by around 30% of the reporting samples. Their own beliefs were quite similar to the explanations they were perceiving.

It is of interest that teacher involvement in conversations pertaining to the medication are reported only to a very limited extent by the child. There may be some underreporting of conversations, but this substantiates the finding in other data indi-

cating that teachers are generally cautious about discussions pertaining to stimulant medication.

One of the important questions that we asked the children was about their own evaluation of the effectiveness of the medication. Almost a third of the children (24% in Grand Rapids and 38% in Kalamazoo) had no opinion about the medication they were (or had) taken. But a plurality of the children, 46% (49% in Grand Rapids and 35% in Kalamazoo) assessed their medication positively. One fifth of the sample was ambivalent. Only 6% in Grand Rapids and 3% in Kalamazoo thought it was bad to be taking the medication. Similarly 87% of the children perceive that their medication helps "very much" (57%) or "some" (30%). (See Table 7.5, Appendix L.) Large majorities (about 60%) report that taking their medication makes their school work easier and makes it easier to be with friends (Table 7.6, Appendix L.)

Seventeen percent of the combined samples said that medication made their work more difficult. A comparable question was asked pertaining to the effect of medication on the ability to be with friends; the percentage responding that medication made it easier to be with friends was similar to those reporting the efficacious effect on school work. There was a higher percentage of children in Kalamazoo (about one-third of the group) reporting that the medication made it more difficult to be with their friends. Generally, the greatest benefits the children perceive from taking medication is that they are calmed down, exhibit improved behavior, and are helped in school performance. (See Table 7.7, Appendix L.) The child's perception of the unpleasant aspects of medication was predominantly focused on the taste and on the taking of pills. These two explanations were the predominant responses by those who did perceive unpleasant aspects of taking medication.

Although a sizable group of the children (about 40%) reported that they felt no different when they did not take their medication, over two-thirds reported that others could tell, mostly their parents and teachers. (See Table 7.8, Appendix L.)

The pattern of medication taking reported by the children reveals the importance of school procedures. While almost all the children indicate they took their medication prior to going to school, two-thirds also tell us they took their medication at lunch time at school. Relatively few children take their medication at any other time (see Table 7.9, Appendix L).

Data from the children indicate a diversity of places in which their medication is administered at school. No single place characterizes this activity in spite of the relative frequency of medication at school.

While it would be incorrect to characterize the children in general as being teased, or treated unfairly because of medication, there is an appreciable perception on the part of children that they were either teased or treated unfairly as a reaction of

others to their medication. (See Table 7.10, Appendix L.) This appeared to be more prevalent in the Kalamazoo sample than in the Grand Rapids sample, probably because more Kalamazoo subjects were in medication treatment at the time of the interviews. Both samples reported the least amount of teasing from siblings and higher percentages from peers. While the data indicated the benefits of medication in getting along with friends, we also found that children believed medication caused them to be picked on or teased by their friends. These data are not intrinsically incompatible. They could well point to differences in the social situation which, in some instances, have caused beneficial outcomes and, in others, harmful outcomes.

In sum, then, children recognized some negative consequences of being on medication and displayed some resistance to it. However, their assessment of the medication was positive and their understanding of its purpose, accurate. The social arrangements of treatments for hyperactivity and communication about it is seen as uncertain and reflects, in the experiences of the children, the uncertainty seen in our analysis of parents, teachers and physicians.

Since we used a large number of open-ended questions, we gathered many comments in the children's own words. These comments augment the data reported on this chapter. Appendix M presents a selection of children's observations organized by topics which are discussed in this chapter. Understanding of the child's world is advanced by leavening the statistical analysis with the words of the children selected not for their typicality but for their presentation of the intensity and flavor of their experience.

CHAPTER EIGHT

PARENT, TEACHER, AND PHYSICIAN ROLES IN CARING FOR HYPERACTIVE CHILDREN

One of the major organizing concepts for this study is that of role. The concept of role provides a way of identifying expected behaviors on the part of individuals who are involved in the diagnosis and treatment of hyperactivity. Our use of role is as expected behaviors rather than actual behaviors. In other words, role means what a person believes ought to be done rather than what is actually done. The focus on expected behaviors provides a way of identifying the more regularized and less idiosyncratic aspects of the care of hyperactive children as perceived by the relevant parties. In our interviews with parents, teachers, and physicians about role, we shifted the focus from their own child, pupil, or patient to the perceptions of what ought to happen for effective diagnosis and treatment of hyperactive children in general.

Three dimensions of role were constructed for the analysis. The first, we termed inclusion (breadth of role). This refers to the extensiveness of behaviors which are deemed to be a part of the role. How many of the 35 behaviors comprising our sample of possible role behaviors are believed to be necessary in caring for hyperactive children? The second dimension we have termed legitimacy. Which persons ought to be involved and which person ought not to be involved in specified behaviors in the diagnosis and treatment of hyperactive children? This refers to the perceived right of various individuals to be involved in the behaviors. The third dimension we have termed dominance, which refers to the perception of who should be the major actor with regard to the particular behavior in question.

In developing the role instrument, we tried to include items which were generally reasonable and which reflected either ongoing practice in the diagnosis and the termination of treatment of hyperactive children or practices which, in pre-tests, in pre-study interviews with parents, teachers, physicians, and consultants would be highly desirable and appropriate. We did not nominate outlandish or esoteric behaviors. Thus, it was not surprising that the mean percentages of agreement on the inclusion dimension were high. Parents endorsed 86.2% of the 35 items, teachers, 88.5%; and physicians, 85.6%. The standard deviation for parents was 20.0%; for teachers, 20.3%; and for physicians, 24.4%. These figures show that the central tendency among the three samples was quite similar and that there was endorsement of most of the items in the role behavior as useful behaviors in the treatment of hyperactive children.

Another way of examining the nature of agreement about inclusion is to consider those items which were agreed to by less than

90% of any of the samples. In the case of parents, 22 or 62.8% had less than 90% agreement. For teachers, 26 or 74.3% fell into this category. For physicians, the number was 23 or 65.7%. This demonstrates a quite high level of agreement among all three samples with regard to the desirability of the behavior sampled by the instrument.

Even though the agreement on inclusion tended to be fairly consistent across samples, we wanted to examine role items for which there were differences among the samples. To do this we noted items which yielded 10% or more disagreement.

Table 8.1 shows that the major source discrepancies were between parents and physicians. On each of the items in Table 8.1, parents and physicians were contested. In those instances when discrepancies involved teachers they were as many times joined with parents as with physicians. Some of the items which yielded discrepancies are of particular interest.

(Table 8.1, following page)

Table 8.1
Items Yielding Discrepancies Among Samples
on the Dominance Dimensions

Items	Percent of Agreement			Description of Contest
	Parent(s)	Teacher(s)	Physicians(s)	
In addition to child's doctor, another doctor or specialist should be consulted.	85%	89%	51%	P/T vs. Ph
The diagnosis of hyperactivity and use of medication should be put into official school records.	65%	79%	81%	P vs. T/Ph
Someone other than the doctor should suggest a possible diagnosis of hyperactivity for a child.	72%	76%	86%	P vs. Ph
The use of medication should be recommended for a child who is diagnosed as hyperactive.	84%	74%	72%	P vs. T/Ph
When a hyperactive child is treated with medication, the use of medication should be explained to other members of the household who are old enough to understand.	94%	95%	84%	P/T vs. Ph
Students in the class of a hyperactive child being treated with medication should have an explanation of the medication treatment.	17%	20%	4%	P/T vs. Ph
A hyperactive child being treated with medication should have an explanation of that medication treatment.	96%	98%	84%	P/T vs. Ph
In addition to medication, other changes should be made in the life of the hyperactive child, such as other treatment and approaches or changes in the home or school situation.	74%	91%	94%	P vs. T/Ph
A program of regular visits to the doctor should be set up for the hyperactive child being treated with medication.	90%	98%	100%	P vs. Ph
There should be a channel of information between the teacher and physician of the hyperactive child being treated with medication.	78%	95%	98%	P vs. T/Ph

Item 22 is of interest because it has been a major theme in the literature. Our data indicate one-fourth of the parents disagreed that it should be a part of the treatment of the hyperactive child. Even though the notion of adjunctive therapy is strongly supported in the literature produced by the medical and educational experts, we find a surprisingly high percentage of parents saying that this should not be done.

It has been suggested to us that physicians and teachers are at fault in failing to provide adjunctive therapy. These data, however, suggest that the explanation that physicians and teachers are prone to take the "easiest way around the problem" should be somewhat qualified. Parents had the lowest level (74%) of agreement with this item (physicians - 94%; teachers - 91%). Some of the disinclination to employ adjunctive therapies may well be the result of resistance from parents. It is worth noting that many of the changes and adjunctive therapies are much more costly and time consuming for parents than the use of medication.

There were two items which did not have at least 65% agreement among all three samples. These two items were item 11 and item 17. Item 11 reads: "Diagnosis should be told to other children in the child's class." Item 17 reads: "Students in the class of a hyperactive child should have an explanation of the medical treatment." Both of these items yielded low percentages of agreement. There is very strong feeling on the part of all participants in the process that neither the diagnosis nor the medication should be explained to the children in the classroom.

These items raise intriguing questions. Data that we will present later indicates that some hyperactive children are subjected to teasing and verbal abuse and that the medication and the condition is discussed. Clearly, however, for the subjects, both medication and diagnosis are somewhat taboo subjects in class discussion. Parents, teachers, and physicians seem to feel that the hyperactive child's diagnosis and treatment is his own business and not the concern of other children. Discussion of hyperactivity and its treatment could be interpreted as stigmatizing of the child by the teacher or other school personnel. On the other hand, data from the children indicate that their classmates do ask questions or refer to the matter of their condition and treatment. This is sometimes done in cruel fashion. There is a question whether an attempt at the education of the child's peers in school should be considered.

Apart from the two items which registered less than 20% agreement, there were two items on which physicians fell below the 65% agreement, with teachers and parents exceeding 65% on these items. These items were: "In addition to the child's own doctor another doctor or specialist should be consulted," and: "A physical examination should be required to determine if medication treatment can be ended." Teachers and parents endorsed these behaviors with fairly high percentages. The percentage of physicians endorsing

this is substantially less. Physicians are somewhat readier to rely on their own expertise than are parents or teachers.

When we examine the beliefs of parents, teachers, and physicians about the dominance dimension of the role item (or the belief about who ought to be responsible for the particular behavior) we find that the sort of inter-sample consensus found about role breadth is missing for dominance. There was disagreement among the samples relative to the person who had major responsibility in implementing or initiating the behaviors which are expected.

Table 8.2
Parents, Teachers, and Physicians
Nomination of Role Dominance

Sample Responding	Sample Designated		
	Parent	Teacher	Physician
Parent	54.74%	17.74%	26.98%
Teacher	41.84%	26.70%	30.40%
Physician	36.90%	19.90%	41.75%

Table 8.2 shows how each sample designated dominance for role inventory. For example, parents indicated that parents ought to be dominant in 55% of all of the role items. The most striking differences are displayed by parents and physicians with regard to the beliefs of the dominance of the physicians. The physicians nominated physicians as dominant in 42% of the behaviors. Parents nominated physicians in 27% of the behavior items. There was a corresponding difference in the designation of parent dominance, with the parents seeing parents as more dominant than did physicians. The teachers fell between parents and physicians in viewing the dominance of the parent and the physician role. Teachers were least frequently specified as dominant by parents, teachers, and physicians. Though teachers saw themselves as dominant more frequently than did parents and physicians, nonetheless they designated themselves as dominant for only slightly more than one-fourth of the role items.

A more substantive examination of role dominance can be provided. We conducted an analysis to look at dominance relative to the particular role items. This procedure parallels the process which we used in the analysis in the inclusion dimension. We set a 66% level as being the level at which a sample would be consid-

ered to reflect consensus about dominance. We found nine items where all samples agreed on the dominant figure:

- 2 - Medical help should be sought for a child who seems to be hyperactive. (dominant figure: parents)
- 5 - Parents should understand the details and meaning of the medical diagnosis of their child. (dominant figure: physicians)
- 11 - The diagnosis of a child who is hyperactive should be told to other children in the child's class. (dominant figure: teacher)
- 12 - Information about the child's behavior at home should be part of diagnosing hyperactivity. (dominant figure: parents)
- 14 - The use of medication should be recommended for a child who is diagnosed as hyperactive. (dominant figure: physicians)
- 15 - When a hyperactive child is treated with medication, the use of medication should be explained to other members of the household who are old enough to understand. (dominant figure: parents)
- 20 - Reports of the child at home should be used to adjust the medication and the times in which the medication should be taken. (dominant figure: parents)
- 24 - Information from home should be used to judge the effectiveness of medication treatment. (dominant figure: parents)
- 26 - Information from the homes should be used to find out if the medication is resulting in harmful side effects. (dominant figure: parents)

These items constitute the core items with regard to agreement about the two dimensions of the role inventory.* It is of interest to note that for six of these nine (and six of the seven items about which inclusion consensus also occurred) which seem to constitute the core of consensus about dominance, the dominant person designated is the parent. This indicates that those role behaviors in which teachers and physicians are nominated as dominant are more contested than those in which the parent is so designated.

A second set of items are examined. These are the items where there was the least amount of consensus about dominance. For these 11 items, none of the three reporting groups achieved the 66% level of consensus. These items were as follows:

- 4 - Information about the child's school performance should be a

*Exceptions to this are items 11 and 14 in which consensus about dominance is high but consensus about inclusion is low.

a part of diagnosing hyperactivity.

6 - The teacher should understand the meaning and diagnosis of her student.

8 - Tests or other diagnostic procedures should be conducted to evaluate the child's condition.

10 - The diagnosis of hyperactivity and use of medication should be put into official school records.

13 - Someone other than the doctor should suggest a possible diagnosis of hyperactivity for a child.

16 - Teachers of a hyperactive child being treated with medication should have an explanation of that medication.

22 - In addition to medication, other changes should be made in the life of the hyperactive child, such as other treatments and approaches or changes in the home or school situation.

25 - Information from the school should be used to judge the effectiveness of medication treatment.

28 - There should be a channel of information between the teacher and the physician of the hyperactive child being treated with medication.

32 - Information from the school should be used to decide whether or not medication should be ended.

35 - A routine follow-up examination and other special assistance should be provided after medication treatment has been ended.

In examining these items we can see that 8 of the 11 items pertain to the school and, indeed, to aspects of the treatment which are particular and unique given the nature of the child's hyperactivity. This set of items suggests that agreement about who should be the major figure in the treatment of the hyperactive child declines in those behaviors that do not constitute routine medical treatment, even if all concerned agree that the behaviors should take place.

Another aspect of decisions about who has the major responsibility to ensure that the needed behaviors occur is depicted in Table 8.3. This table shows a "collaboration index" of two types and "set breaker" index. Type 1 collaboration indicates the designation of shared responsibility involving the person who is reporting, i.e., parents saying that the responsibility should be shared on a particular item between parents and physicians or parents and teachers. Type 2 indicates collaboration on dominance which does not involve the reporting person, i.e., parents saying the collaborative dominance should be shared by teachers

and physicians. The set breaker index indicates the propensity to name persons other than physician, teacher, and parent such as psychologist, social worker, or others, as being dominant on a particular behavior.

Table 8.3

Percentage Response of Parents, Teachers and Physicians to Two Types of Collaboration and to Underrating of Other Persons as Dominant

Respondents	Collaboration in Dominance with Self	Collaboration in Dominance without Self	Other person Dominant (set-breaker)
Parent	9.96%	1.64%	4.54%
Teacher	12.97%	5.58%	8.15%
Physician	19.25%	8.52%	13.24%

Turning to the items themselves we found that for only one item did more than 20% of the samples specify that "others should be involved." That was item 8: "Tests and other diagnostic procedures should be conducted to evaluate the child's condition." We think this represents an understanding on the part of the respondents that others, both inside and outside of the three systems involved, have the specialties and techniques to conduct these diagnostic procedures. For the parents and teachers, there were no other items in which "others" were nominated by more than 20% of the samples.

In addition to item 8, more than 20% of the physicians indicated three other items in which "others" should be involved. These items were:

6 - Should the teacher understand the details and meaning of the medical diagnosis of her student?

10 - Should the diagnosis of hyperactivity and the use of medication be put into official school records?

22 - In addition to medication, should any other changes be made in the life of the hyperactive child, such as other treatments and approaches or changes in the home and school situation?

None of these three items involved the medical care of the child.

Turning to the collaboration index we found two items on which all three groups agreed, exceeding the 20% criterion level, that combinations of persons should be responsible. The items to which all three samples agreed were "In addition to medication other changes should be made in the life of the hyperactive child, such as treatments, approaches and changes in home and school situation," and "A hyperactive child taking medication should be given each dose by an adult." Both of these items require attending to the child in more than one system setting and situation. All the items on which teachers and parents exceed the 20% criterion level for shared responsibility are items involved with treatment (item 34), or termination (the remaining four items). Each of these items reflects the notion that treatment or termination cannot be initiated or major responsibility taken by only one party; all require some combination of actions and behaviors on the part of the parent and the physician. The role item (item number 1) that parents, teachers, physicians and others should be responsible for finding out if the child might have behavior and learning problems, by its structure involves several people simultaneously. The eighth item, proposing that another diagnostic procedure be used to evaluate a child's condition, has been discussed in another context and involves the use of other members of both the educational and medical social systems to conduct these tests. The final item, 13, "Someone other than a doctor should suggest possible diagnosis of hyperactivity for a child," apparently is seen by physician and teacher as a joint recommendation that a combination of people should suggest this to a physician.

Worthy of note are the items that a high proportion of teachers alone see as requiring a combination of others. Forty-six percent of the teachers indicated that they thought a combination of persons should be involved when "parents of a hyperactive child should be provided with support and reassurance about their child and the treatment given their child." While neither parents nor physicians saw a combination of people involved in this, the teachers seemed to feel that this is not the responsibility of any one person (themselves, or the physician), but requires a multitude of skills and a multitude of reassurances.

The third dimension of the role instrument pertains to legitimacy of involvement. As Table 8.4 indicates, each reporting sample accorded the highest level of legitimacy for itself, i.e., the highest perception of legitimacy in the parent column was the report of parents, the highest for teachers was the teacher sample, and so on. In absolute percentages, however, teachers rated physician and parents higher than teachers. Parents and physicians had lower ratings for the legitimacy of teachers than did teachers.

In order to specify items which indicated particular concern about the illegitimacy of involvement of system members, we used a 50% criterion level as a useful cutoff point. With regard to physicians reporting on the parent role, there are two items which

exceed the 50% level (i.e., 50% or more physicians considered parents illegitimate in relation to the behavior). These behaviors were: "The diagnosis of hyperactivity and the use of medication should be put into official school records" (51%); "The use of medication should be recommended for a child diagnosed as hyperactive" (58%).

It is not surprising that the physicians consider the entry of materials into the child's school record as illegitimate for the parents. The other item is of more interest. A majority of physicians felt that parents should not be involved in the recommendation of a medication. This item was phrased to provide a conservative form of involvement, "recommend" rather than "request" or "demand." Nevertheless, parental involvement was not considered legitimate by the majority of physicians.

Table 8.4

Parent, Teacher, and Physician
Designations of Legitimacy*

Respondents	Parent	Teacher	Physician
Parent	69.79%	27.40%	41.13%
Teacher	59.16%	40.84%	47.99%
Physician	52.76%	29.83%	57.52%

*Respondents could indicate more than one actor as legitimate: percentages therefore exceed 100.

One item emerges when examining what behaviors 50% or more of the parents think the physician is illegitimate in. This item states: "When the hyperactive child is treated with medication, the use of medication should be explained to other members of the household who are old enough to understand." In a way, it may not seem unusual that a high percentage of parents would view the physician as illegitimate, since in most instances the way in which medical care is delivered would preclude such a procedure. Typically, a child is brought in for medical care and the physician dispenses such care in ways which would make the providing of information and counseling to other members of the family not feasible.

It should be pointed out, however, that in the days of the "old family doctor" a more holistic approach to medical services

to family (an attempt is being made to revitalize this by family practitioners) would have made this behavior on the part of physicians feasible and perhaps, accordingly, more normative than the respondents indicate that it is. It's also worth noting that, with the concern in the literature about the attaching of stigmata to hyperactivity, the behavior that stems from hyperactivity, and the treatment of hyperactivity particularly by extended family, the parents' disposition on this attitude would exclude the most knowledgeable and practiced explanation of the child's condition to other members of the family--even if the physician were disposed to provide this service.

Once again, the tendency to proscribe teachers from involvement is evident. There are 13 items on which 50% or more illegitimacy designations are specified by parents, teachers, and physicians as with regard to teachers. This coincides with the information presented in Table 8.4.

By way of summary, we find that there is comparability with regard to the beliefs about the inclusion of behavior in the role of treatment of hyperactive children. Thirty of the items were endorsed by parents with either high (90% to 100%) agreement or moderate (75% to 89%). Thirty-one of the items were endorsed by teachers with high or moderate consensus, and 30 of the items were endorsed by physicians with the same degrees of consensus. Relatively few of the items resulted in low levels of consensus or were rejected. Only 2 of the 35 items received more of a "should not" response than a "should be done" response on the part of teachers. Only three items were so responded to by teachers and physicians. This is not surprising since the items that were selected for inclusion in the role instrument were not selected in order to represent a wide spectrum of beliefs about behaviors, but rather constituted a sampling of behaviors commonly engaged in while contemplated by those who had the care of hyperactive children.

With regard to the question of who should be dominant in implementing these behaviors, we find that each sub-sample tended to nominate itself more frequently than it nominated any of the other sub-samples. Parents nominated themselves as being the dominant person with regard to role behaviors on 13 of the items; they nominated teachers on 5 of the items and physicians on 5 of the items. Teachers nominated parents on 9 of the items; they nominated teachers on 7 of the items and physicians on 3 of the items.

Physicians nominated parents as being the dominant actors on 8 of the items; they did not nominate teachers on any of the items and they nominated physicians on 12 of the items. There was a sharp disagreement among physicians, teachers, and parents as to the dominance of physicians. Physicians nominated themselves on about one-third of the items as the dominant actors; teachers nominated them on 3 items and parents on 5. It is worth

noting that parents saw themselves, as we have noted, as being dominant on 13 of the items. They saw teachers and physicians dominant on the same number (5) of items. Together these data suggest that there is a considerable difference among the three samples with regard to the persons who are accountable for carrying out the major responsibility for the behaviors that were indicated as being desirable or expected.

With regard to legitimacy and illegitimacy, all samples regarded the teacher as having the role with highest levels of illegitimacy. Teachers were nominated as illegitimate on 22 of the role items by parents (63%) and on 18 of the items (51%) by teachers and physicians. Parents were nominated more often by teachers as being illegitimate (10 times, or 19%) than they were nominated by any of the other two samples. One other general index which provides an insight into these data is the number of times when there is an open cell with regard to the dominance. This would indicate uncertainty and high degree of difference among the three samples indicating internal disagreement about who was responsible for the behavior. The least amount of this is evidenced by the parent sample. Only 6 cells out of a possible 35 (17%) were left blank, indicating that no actor was nominated for at least 50% of the parents for those 6 items. For teachers the number of open cells was 12, or 34%, and for physicians it was 11, or 31%.

Summarizing this overview, we make the following observations. First, there tends to be considerable agreement among all three samples about the inclusion of behaviors in the treatment of hyperactive children. The samples, as groups, do not seem to show much variability with regard to the extent of the breadth of the role as pertains to hyperactive children. There does seem to be somewhat greater disagreement with regard to the domination of legitimate and the reciprocal concept of illegitimate actors in regard to the behaviors. This category is of potential importance since it is one that leads to considerable disagreement among people of different social systems and is, in a sense, a direct conflict among members of social systems.

There is, perhaps, even more disagreement on an issue which may be even more important--the question of who has the major responsibility for seeing to it that the behavior is carried out. Here we observe occasions of sharp disagreement among the three samples in some instances, with one group viewing it as prerogative of one of the groups and another group nominating a different actor. And in other instances we find that the percentage of response is split over a series of various nominated actors.

The best single index of the extent of argument may be found in the observation that, on only 8 (22%) of the 35 items, there was reasonably close agreement among the three samples about whether or not the behaviors should be carried out, who was responsible for seeing to it that it was carried out, and who were the legitimate and illegitimate actors vis-a-vis the item.

CHAPTER NINE

THE MODES OF SOCIAL SYSTEM INTERACTION IN THE TREATMENT OF HYPERACTIVE CHILDREN

In Chapter Eight we examined the beliefs of parents, teachers and physicians about their roles. A fundamental aspect of this research is that the extent to which roles fit together constitutes an important element in the provision of care for hyperactive children. In essence, a role analysis provides a way of examining specifics of articulation, or lack of articulation, between the salient persons responsible for the care of hyperactive children.

Unlike the analyses of the role instrument (presented in Chapter 8), which focused on the expected behaviors of parents, teachers, and physicians as the relevant adults in the treatment process of the hyperactive child, this analysis focuses on the patterns and the degree of agreement among the members of the three social systems (familial, educational, and medical), parents, teachers and physicians, as aggregated by the set of adults surrounding each hyperactive child. We will therefore analyze the social system relationships by comparing the parent, teacher, and physician role expectations for each child in the sample.

As with our prior analysis, we break role into three components so that the relevant adults representing the three social systems can be seen to agree or disagree with each other about the treatment of hyperactive children in three ways: inclusion, dominance, and legitimacy. Inclusion refers to the belief that a behavior toward the hyperactive child should be engaged in; dominance refers to the expectation of who should take responsibility for initiating the behavior and legitimacy refers to the expectation of who should be involved in the enacting of the behavior. For example, one of the items on the role inventory reads "Should a hyperactive child being treated with medication have an explanation of the medication?" The interview inventory was conducted in order to ascertain whether the respondents believed that such behavior should be carried out (inclusion), who they thought should have prime responsibility for carrying out this behavior if it were to be carried out (dominance) and to obtain an indication by respondents of all of the persons perceived to be legitimate in regard to the enacting of the behavior (legitimacy). Agreement among the dyads for each hyperactive child on each of these three role dimensions will be analyzed.

There are consequences in the treatment of the hyperactive child if individuals responsible for the treatment disagree or agree on inclusion, dominance, and legitimacy. If the adults in the child's world disagree on inclusion when cooperation is required, then the likelihood that behavior will be enacted to treat or cope with the child's hyperactivity is strongly reduced. These situations may create a chaotic environment for the child who is

already suffering from a socially disabling disorder. If the adults in the child's environment fail to agree on dominance, it may mean that behaviors mutually agreeable may not be undertaken because there is no consensus about who is responsible for initiating and carrying through the behavior. It may also mean that if one person initiates a behavior their right to do so may be challenged by others in the child's environment, thus causing a tug-of-war in the attempt to cope with the child's disorder. Disagreements regarding legitimacy mean that the adults disagree about who should be involved in the behavior. Conflict and abortive behavior can result from this sort of disagreement. Lack of agreement on any of the dimensions of the role reduces the probability of concerted behavior, but each dimension does so differently.

Our respondents, when being questioned about expected behaviors toward the hyperactive child in the role inventory section, were asked to base their answers on the treatment of or their expectations about their child. The instructions they received now were "Before we were talking about (child's name), but now we will be talking in general about children who have been treated for hyperactivity. The next questions will deal with your view of what parents, teachers, and doctors should or should not do for hyperactive children and whose job it should be to do it. I would like to find out what you think should happen rather than what actually happened."* In avoiding the reference to the individual child, we are explicitly exploring the world of general expectation as reflected through the adults who do care for hyperactive children.

The analysis by dyads of individual children (their parents/teachers, parents/physicians, teachers/physicians), when aggregated over cases of hyperactive children, provides us with a picture of the extent of agreement that exists in the three social systems as they have impinged upon hyperactive children. In a sense, it provides a sampling of the convergence of the systems and the amount of agreement that is to be found when the three systems converge around hyperactive children.

*While we are certain that there was some contamination of the general views expressed, by the experiences of the respondents, the attempt to keep the comments general and generic was made by our interviewers. It is our feeling that the responses to the role items did constitute an abstract view in distinction to the responses on the earlier part of the interview which were explicitly directed toward the child under consideration.

Dyad Analysis

The proportion of agreement about role inclusion, dominance, and legitimacy for the dyads of adults caring for hyperactive children is recorded in Table 9.1. By agreement in the inclusion dimension, we mean when both members of the dyad agree that a role behavior was appropriate or both members of the dyad agreed that a role behavior was inappropriate. Agreement for dominance meant that both members of the dyad agreed about the person who should initiate and/or be responsible for the behavior. This was opposed to explicit disagreement where one member of the dyad stated that a given person should be dominant in the behavior while another member of the dyad explicitly stated that a different person should be the dominant figure in the behavior.* Dyadic agreement for legitimacy occurred when both members of the dyad agreed that the same person was legitimately involved in behavior or when they agreed that the same person was not legitimately involved in the behavior.

Table 9.1 shows the amount of dyadic agreement in the sets by dyad and by role dimension. Inspection of this table shows that there is uniformly high agreement, approximately 85%, across all three dyads in the inclusion dimension. This reflects, in part, the nature of the items. The role inventory was comprised of items which were conventional and reasonable in the recognition, diagnosis, and treatment of hyperactivity. Parents and teachers, parents and physicians, teachers and physicians--all tended to agree strongly on what items should be included and what items should be excluded in the care of the hyperactive child.

The dominance dimension is quite different. There is only about 40% agreement among all three dyads. As with inclusion, the three types of dyads are very similar. Unlike inclusion, however, there is substantial disagreement, more disagreement than agreement, about who should be dominant in enactment of behaviors about hyperactive children.

The third dimension, legitimacy, indicates an even greater amount of disagreement. There is approximately 20% agreement among all three dyads about who should be involved in these behaviors, and who should not. The amount of disagreement about legitimacy indicates a great deal of incoherence in the expectations of the adults in the light to hyperactive children. The extent of disagreement for dominance and legitimacy does not necessarily mean that the behavior will not occur, but it may mean that it will occur in a disjointed, inconsistent, or conflict-ridden fashion, with the participants pulling and tugging for

*In those instances where one member of the dyad mentioned several people and another dyad member mentioned others with some overlapping of personnel, these responses were set aside and not made part of the analysis.

Table 9.1

Agreement Among Dyads of Parents, Teachers, and Physicians
About Behaviors Toward the Hyperactive Child

Role Dimension	Parent/Teacher Dyad Agreement		Parent/Physician Dyad Agreement		Teacher/Physician Dyad Agreement	
	f	%	f	%	f	%
Inclusion of proposed behavior in regimen of child (INCLUSION)	2580	85.26	3542	85.23	2102	84.18
Specification of person respon- sible for proposed behavior (DOMINANCE)	1014	41.19	1377	41.85	732	37.18
Specification of persons legiti- mate to be involved in proposed behavior (LEGITIMACY)	332	21.63	391	18.70	221	18.00

"proper" expression of the behavior according to their own beliefs. This is not inconsistent with the expression of conflict in the literature and is a powerful commentary on the need to understand the full social aspects of the diagnosis and treatment of hyperactivity in children.

The distribution of dyadic agreement by dyad (Table 9.2, Appendix N) indicates that there is a normal distribution of the amount of agreement among the three types of dyads (parent/teacher, parent/physician, teacher/physician) for all three of the role dimensions. For the very high agreements on the dimension of inclusion, all three dyads have means of about 85 and standard deviations of 7.7. All are in the same range of 62% to 100% agreement in distribution. This constitutes extremely high consensus and a similarity among all three of the dyads in their proclivity to agree on inclusion. Analysis of the three dyads for dominance shows an essential similarity also. Though at much lower levels of agreement, their means are all ranged between 37% and 42% with standard deviations ranging from 10 to 14. Slightly lower mean and standard deviations (37 and 10) are seen in the teacher/physician dyad. The ranges of the distribution run from 12% to approximately 70% for the parent/teacher, parent/physician dyads and a little lower, 10% to 64%, for the teacher/physician dyad. Lower means, larger standard deviations and a greater range of scores characterize the three dyads in distribution of agreement of legitimacy. The means range from 17% to 21% agreement; standard deviations range from 12 to 13. The range of agreement is 0 to 60 for the dyad of parent/teacher, from 0 to 77 for the dyad of parent/physician and from 0 to 50 for the dyad of teacher/physician. The major variation is by component of role element rather than by the type of dyad. Among the social systems that deal with hyperactive children, the difficulty on deciding dominance and inclusion is found to a relatively equal extent among the three dyads investigated, and the relative proclivity to agree on inclusion is also found to the same extent among the three dyads.

An examination of the dyadic agreement by role item is also illuminating. Our analysis indicates that there are several role items that have particularly low scores on dominance and legitimacy. By particularly low scores we mean that less than 20% of the dyads agree about dominance and less than 10% agree on legitimacy. If we pay attention to those items that appear to have little agreement across all three dyads, a pattern emerges. These are items that are essentially inter-system, informational, or behavioral items which call for behaviors requiring cross-system communication or activity. In these cases, the members of the dyad disagree with one another in determining who should be dominant and who is legitimate in this process. This seems to be particularly the case when the school and the medical system are involved simultaneously. Some of the items that are low in both dominance and legitimacy are: "Should information about the child's school performance be a part of diagnosing hyperactivity?"; and "Should the teacher understand the details and meaning of a

medical diagnosis of her student?"; and, "Should the child understand the details and meanings and medical diagnosis of his/her condition?" (The lack of agreement on this is particularly notable in the teacher/physician). In the two dyads in which the physician is a part, the role item, "Should someone other than the doctor suggest to the doctor a possible diagnosis of hyperactivity for a child?" is one with extremely low dyadic agreement. If we turn our attention more exclusively to legitimacy, we note that three role items are extremely low on legitimacy: "Should information from the home be used to find out if medication has resulted in harmful side effects"; "Should there be a channel for information between the teacher and physician of a hyperactive child being treated with medication?"; and, "Should a routine follow-up examination and other special assistance be provided after medical treatment has ended?" These behavioral expectations, all of which have dyadic agreement in inclusion, are not inconsequential in the treatment regimen of the hyperactive child. They do seem to be representative of the "falling in the cracks," between systems that we have noticed in the interviews and in our other analyses.

Set Characteristics

The first step in characterizing the sets was to develop an Index of Agreement. The Index of Agreement for each dyad was calculated by adding the percentages of agreement across the three role dimensions: inclusion, dominance, and legitimacy. Therefore, if the parent/teacher dyad of a given set had 85% agreement in inclusion, 42% agreement in dominance, and 23% agreement in legitimacy, the index score for that set would be 149. Since the Index of Agreement score was created by adding three percentages, the lowest possible score was zero and the highest possible score was 300. The distribution of the index of agreement by dyad is to be found in Table 9.2 in Appendix N.

The three types of dyads are quite similar in their index of agreement. The parent/teacher dyads have a mean index score of 148, the parent/physician dyads 146, and the teacher/physician dyads 140. All of these means are below the theoretical midpoint of 150. The index of agreement for all three dyads, therefore, reflects more disagreement than agreement on behavior. The standard deviations of all three dyads are also very similar. They are 22.8 for the parent/teacher and teacher/physician dyads and 22.0 for the parent/physician dyads. The distribution of the Index of Agreement scores for all three dyads is normal. Plus and minus one standard deviation accounts for 60% of the parent/physician dyads and 71% and 72%, respectively, of the parent/teacher and teacher/physician dyads.

Although the distribution of the index of agreement shows the amount of agreement by dyad to be quite low in absolute terms on two of the three components, we can investigate the characteristics of those sets relative to the distribution. In order to do this, we calculated the scores one standard below and one stan-

Table 9.3

Set Classification by Dyad Designation on t

Set Type by Index of Agreement	Total		Parent/Teacher								Par	
	High		Moderate		Low		High		Moderate		Low	
	f	%	f	%	f	%	f	%	f	%	f	%
High, High, High	1	1	1	100	-	-	-	-	-	-	1	100
High, High, Moderate	3	4	2	67	1	33	-	-	-	-	2	67
High, Moderate, Moderate	19	26	7	37	12	67	-	-	-	-	4	21
Moderate, Moderate, Moderate	21	29	-	-	21	100	-	-	-	-	-	-
Moderate, Moderate, Low	16	22	-	-	11	69	5	31	-	-	-	-
Moderate, Low, Low	7	10	-	-	0	0	7	100	-	-	-	-
Low, Low, Low	1	1	-	-	-	-	1	100	-	-	-	-
High, Moderate, Low	3	4	0	0	2	67	1	33	0	0	0	0
High, Low, Low	1	1	1	100	-	-	0	0	0	0	0	0
TOTALS	72											

*This analysis is confined to those sets in which
role data from three dyads were available.

ble 9.3

gnation on the Index of Agreement*

r	Parent/Physician						Teacher/Physician					
	High		Moderate		Low		High		Moderate		Low	
	f	%	f	%	f	%	f	%	f	%	f	%
-	1	100	+	-	-	-	1	100	-	-	-	-
-	2	67	1	33	-	-	2	67	1	33	-	-
-	4	21	15	79	-	-	8	42	11	58	-	-
-	-	-	21	100	-	-	-	-	21	100	-	-
31	-	-	10	62	6	38	-	-	11	69	5	31
100	-	-	3	43	4	57	-	-	5	71	2	29
100	-	-	-	-	1	100	-	-	-	-	1	100
33	0	0	1	33	2	67	3	100	0	0	0	0
0	0	0	-	-	1	100	0	0	-	-	1	100

dard deviation above the mean for the distributions of each dyad on the Index of Agreement. The parent/teacher dyad agreement scores above 171 were considered high, the low 125 considered low and those in the middle considered moderate. The cut-off point for the teacher/physician was: 163 and above were high, 117 was the low for low and those in-between were moderate. We then divided our sets into those that consisted of one dyad, where only two of the interviews could be completed, and those with three dyads.*

Seventy-nine percent of the sets were one-dyad sets. Of these, 11 were high agreement sets, 46 moderate agreement sets, and 12 low agreement sets. (See Table 9.3) Two of the high agreement sets consisted of the parent/teacher dyad, and 9 consisted of the parent/physician dyad. Of the moderate agreement sets, 13 were parent/teacher dyads and 33 parent/physician dyads. Of the low agreement sets, 3 were parent/teacher dyads and 9 parent/physician dyads. In all of the one-dyad sets, 26% were parent/teacher dyads, and 73% parent/physician dyads. There is no indication from these data that there are any differences between the high, moderate, and low agreement sets in terms of the sort of dyad that comprised these sets.

There are 72 three-dyad sets. Of these 72 sets, only 1 consists of 3 dyads with high agreement. Three sets are comprised of 2 dyads with high agreement and 1 dyad with moderate agreement. There are 19 sets in which there is 1 dyad with high agreement and 2 with moderate. The modal category (traceable to our method of categorizing dyads) contains 21 sets comprised of all moderate dyads. Sixteen sets are comprised of 2 moderate and 1 low agreement dyad and 7 sets are comprised of 1 moderate and 2 low dyads. There is 1 set in which all 3 dyads are of low agreement. There are 3 sets in which there is 1 dyad each with high, moderate, and low agreement and 1 set in which there are 2 low agreement dyads and 1 high agreement dyad.

Even among these "relatively" high and low agreement sets, we find relatively few sets comprised of two or more high agreement dyads. Only 50% of our three-dyad sets fall into this category. The proportion of children in our sample who live in an environment in which the three adults, representing the three so-

*Some of these were one-dyad sets because we were not permitted by the parent to interview the teacher or the physician. In other one-dyad sets, the teacher or the physician declined to be interviewed although the parent gave us permission to approach these professionals for the interview. Other one-dyad sets occurred because the child fell into the categories we labeled as "second order termination." Children of this category had terminated stimulant medication more than two years before the collection of the data. For children in this category interviews with the teacher at the time of the stimulant termination were not attempted. The logistics of locating these teachers plus the nature of such retrospective data seemed to impede the collection of these data.

cial systems providing the medical and educational treatment for the condition of hyperactivity, agree with one another is few, very few. This is even more striking when we remember the absolute distribution of the Index of Agreement scores and note that even the high agreement dyads are so categorized in the distribution by having only slightly more agreement among the members of the dyad than disagreement.

The other data in Table 9.2 provide an analysis of the level of agreement by type of dyad when considered by type of set. We see that among the sets characterized by 2 high and 1 moderate dyad, 67% of the parent/teacher dyads are high agreement, 67% of the parent/physician dyads are high agreement, and 67% of the teacher/physician dyads are high agreement. Since this set consists of 2 high and 1 moderate agreement dyad, this distribution is precisely what probability would indicate. The situation is different, however, when we consider the 19 sets with 2 moderate and 1 high agreement dyad.

If the high dyads were distributed evenly among the three types of dyads, one would expect 33% high agreement in each of the three dyads. This is not the case. A disproportionately low number of parent/physician dyads are high agreement (21%) and reciprocally a higher proportion of parent/teacher dyads of moderate agreement (79%). A disproportionately high number of teacher/physician dyads (42%), however, have high agreement. The same pattern is reflected in the sets consisting of 2 moderate and 1 low dyad. There is a somewhat greater proportion of low agreement dyad among the parent/physician dyads in this category of sets (38%). In the moderate, low, low, 100% of the parent/teacher dyads are low agreement dyads (where probability would dictate only 67%) while 57% and 29% respectively are low agreement dyads among parent/physician and teacher/physician dyads.

The point of this analysis is to underscore the idea that the amount of agreement found in each set will have a different meaning depending where, in which dyad of the set, that agreement is found. The tensions indicated in the data for question three between parent and physician are also reflected, to some extent, in this analysis. It is difficult, perhaps even pointless, to attempt to characterize one set of dyadic disagreements as more important or disabling than another. Nevertheless, a child who is in a situation where there is disagreement between the parent and the physician will have different kinds of difficulties and incapacities than a child in a situation where the disagreement is between the teacher and physician. Different aspects of the process of identification, diagnosis, treatment, and termination will be affected.

These analyses of dyads and sets reflect the potential for agreement in behavioral expectation among persons of different systems in which the hyperactive child lives. The data indicate strongly that there is relatively little agreement. This picture of an incoherent and fractured environment for children whose dis-

order already severely limits their ability to function in their social and physical world has yet other overtones.

In asking parents, teachers, and physicians to respond to a general set of behavioral prescriptions for the hyperactive child, we removed them from their own experiences and their predilections concerning the child whose welfare was directly in their hands. In so doing, we tried to evoke the most general patterns of behavioral prescription for hyperactive children in samples of adults who have some first-hand knowledge of the condition. We set the stage, perhaps, for the greatest possible agreement. Our analyses of attitudes and beliefs about hyperactivity and the treatment of the child in their keeping, stress (or left room for) disagreements among the parents, teachers, and physicians about their own charge to emerge. In this analysis of dyadic and set agreement, we attempted to develop a "best of all possible worlds" chance of agreement among the members of the three social systems. This report of the incoherence among the three social systems as analyzed by dyad and set indicates that the integration possible is relatively small across the dimensions of dominance and legitimacy. Although there is high agreement about what should or should not be done, there are marked tensions among all three dyads with some special tensions among parents and physicians about who should initiate these behaviors and who should be included in them. The disagreement about who should be responsible for the behaviors and further disagreement about who should or who should not be involved defines the specifics of the incoherence of the social context of the diagnosis and treatment of hyperactive children.

CHAPTER TEN

CONCLUSIONS AND IMPLICATIONS

Introduction

The data that we have presented in chapters four through nine are compelling, but do not quite speak for themselves. The results of this research inform us about the lives of the hyperactive children and the nature of the society in which they live. The data point to the need for policy and to directions in which policy may be developed. This concluding chapter is devoted to these considerations.

Prevalence

The prevalence data we examined contained surprises for us. We did not expect a prevalence rate as low as that which we found for the medical diagnosis of hyperactivity or for treatment with stimulants. Our findings for diagnosis and treatment were substantially lower than almost any comparable figures in the literature.

We do not know why the estimate is so much lower than previous estimates and guesses made by others. One possibility is that the previous beliefs about the prevalence of the diagnosis and treatment of hyperactivity were accurate, but that there has been a turning away from the propensity to diagnose and treat. We have seen some indication of this in our study, but it is impossible to document the magnitude of this phenomenon. It is also possible, for the reasons advanced earlier, that the prior estimates for the prevalence of hyperactivity were simply incorrect. While expressions of an "epidemic" of hyperactivity seem unwarranted, the prevalence of the condition is high enough to necessitate concern from medical and educational authorities.

The concept of a multiple treatment approach seems to be seldom implemented. If stimulant medications are intended as adjunctive to other therapies (as the manufacturers state), medications are not being used in that fashion. Few children receive more than one treatment and many potential treatments for hyperactivity are rarely applied.

As we saw in chapter four, the proportion of children in the school system diagnosed as hyperactive was small and the proportion of currently treated children was even smaller. If, however, we were to use information about diagnosed or treated children as an index of the amount of concern about this problem within the school system, we would probably underestimate the amount of concern. Based on the data from the teachers and the parents, the pool of candidates within the school system for possible diagnosis as hy-

peractive was estimated at between 3.65% and 4.96%--in spite of the relatively small proportion of children diagnosed by a physician as hyperactive and the smaller proportion of currently treated children. For some policy or procedural considerations, it is reasonable to expect that parents and teachers of children in this undiagnosed pool, in addition to parents and teachers of diagnosed and treated children, may be concerned and involved.

We have no reason to assume that the data gathered from Grand Rapids, Michigan, are very different from other similar communities. More studies of prevalence, however, are needed in order to assess the size of the problem, to plan policy, prevention, and treatment, and finally to free ourselves from the tyranny of myths about the nature of hyperactivity and its treatment.

Controversy and Context

The fundamental question embodied in the controversy over hyperactivity is: Is the diagnosis of children as hyperactive, and their treatment with stimulants, a beneficial or a harmful activity? Few would be categorical in their endorsement or condemnation. Both critics and proponents recognize that the diagnosis and treatment of hyperactive children is fraught with problems. Both camps acknowledge that there are problems in case finding. Both recognize that there is a failure, at times, to employ approaches which address the range of problems encountered by the hyperactive child. Both recognize problems in the management of the monitoring and the maintenance of the regimen. Both acknowledge some possibility (though to different extents) that treatment may lead to labeling that works to the detriment of the child.

This research was conducted because we believed that the question posed above could not be answered solely by additional pharmacological or medical research. We believed that an understanding was required of how the people who are involved in decision-making relative to these questions function and interact. Our approach was to conceptualize a social perspective which was articulated and elaborated as a framework for our empirical research. The fundamental premise of our research was that the diagnosis and treatment of hyperactivity is a social act involving medical and educational aspects; for, if hyperactivity is confined to the technical perspectives of medicine or education, the problems which have been perceived can never be resolved.

Our data illuminate what is involved when we recognize the scope and nature of the social aspects of the treatment of hyperactive children. In the course of our interviews, we have spoken with parents who have told us of the years in which their children's problems have gone unrecognized by the school system. We have evidence of the battles between physicians and teachers in which the child becomes the unwitting victim. We have been in-

formed, in painful detail, about the children placed on stimulant medication by the physician whose regimen is strongly opposed by the teacher, with the result that the child and parents are caught in a tug-of-war between experts. We have seen bewildered, unhappy, and frightened teachers equipped with too little information about the condition and treatment of the children in their care, and who feel hopelessly isolated from the physicians and the medical treatment being given these children. We have seen these and what strikes us as just about all other conceivable consequences of the lack of coordination.

When our respondents speak of their experiences with hyperactivity, they speak of it in terms of the social, interpersonal, and educational factors that comprise their reality. Neither the condition nor the treatment is confined to the medical aspects. The merging of the various aspects into a single life experience is evident. There is a sense of frustration, anger, and sometimes fear that runs through many of the interviews. Yet, in the same interviews, there is often an expressed belief that the diagnosis and treatment of the child was correct and helpful.

In contrast to this holistic perception of the effects of the disorder and the application of medical and social treatments, our data specify the fragmentation of the experiences of hyperactive children, their families, and others involved with them. The data indicate that parents and physicians each nominate themselves as legitimate and dominant. A contest for legitimacy and dominance is evident between the parents and the physicians. Both parents and physicians see the teacher as rarely dominant and often not legitimate, and teachers concur. Teachers also tend to agree with the parents in their definition of who should be dominant and who should be legitimate.

Physicians, who have great power, do seem to be "odd man out." This is certainly more debilitating to coherent action in social systems organization than if, for example, the teachers, who have least salience in the situation, differed significantly from the parents and/or the physicians. Our analysis indicates extremely strong incoherence because of the nature of the responses of these competing adults.

How must the world appear to a hyperactive child whose physician believes that he is the person who should be explaining the details of the condition to the child but whose parents believe that it is their prerogative to do so, and that it is not the physician's business to explain this to the child? How must the world appear to a hyperactive child whose teacher believes that the teacher should not be involved in the diagnosis and whose parents believe that it's the teacher's job to provide needed information to the physician.

As we have been involved in this research, some have said to us that hyperactive children are totally unaware of these factors in the treatment. We know this not to be true. It seems clear

to us that the confused, disjointed, and conflicting pattern of expectations can be of little value in providing a beneficial treatment program. The education and medical treatment of the hyperactive child is being carried on in an incoherent environment.

How can we understand the failures, difficulties, and problems that are encountered in the diagnosis and treatment of hyperactivity? If one uses the medical model, conceiving of hyperactivity as an organic pathology and of the treatment as a response to that pathology falling within the exclusive realm of physicians, there is the likelihood that the problems encountered are seen as random, idiosyncratic, uncontrollable, and only marginally the responsibility of the treating physician. Teachers, parents, or physicians who view the situation in this way will tend to explain the difficulties as the consequences of a "crazy teacher," an "uncooperative parent," or an "incompetent physician." The social systems approach provides us with concepts which explain why the problems of role articulation occur. To explain all of the incoherence we have observed as "craziness or incompetence" is to enter a conceptual cul-de-sac which is unlikely to provide explanatory power or corrective behavior.

The issue that is uppermost in the minds of many who are concerned with the diagnosis and treatment of hyperactivity is the resolution of these problems. We believe that the approach we have taken is useful for several reasons. From our framework, it is possible to remove many of the attributions of blame and guilt which compound the problems of achieving a solution. Those of us who are concerned about finding ways to increase communication recognize that we cannot get physicians to incorporate educational factors by castigating them for their arrogance and rigidity. What these data do is substitute the notion of social systems inadequacy for the notion of evil. Explanations of callousness, laziness, evil, and the like are not required to understand the difficulty besetting our ability to deal with hyperactivity.

Along these lines, a word of advice: Those who seek to write compelling muckraking books and articles about the situation are best advised to not do as we have done, not to sit down and talk at length with the involved persons. When one does this, it becomes more difficult to see villains. One is more impressed by the general desire on the part of all parties to do a decent job and to do what is right for the child, even though one sees shortcomings, errors, mistakes, and problems. We uncovered dedicated, but incapable saviors working in flawed systems.

The approach that we have taken has another important consequence. It equips us with concepts that are helpful in implementing suggestions found in the literature. This is best illustrated by the often cited recommendations by physicians and educators concerning the need to make a place for parents and teachers in diagnosing and treating hyperactive children. If one is obli-

vious to the structural deficiencies which are responsible for generating problems, then one tends to feel that one can "talk a place" for these other participants. We say that participation is desired and welcomed and then expect that participation will follow. It seems clear that it is not until one understands the full meaning of the word "make" in the expression "make a place" that the needed collaboration can occur.

To "make a place" for participants in caring for hyperactive children means to create those social structures, within medical practices, schools, families, and other caretaking organizations, that make participation necessary rather than permissible. It means that the educational plans for the hyperactive child are defined as incomplete until the physician's contribution is incorporated. It means that we act on our belief that information from school personnel and parents is essential in understanding the child's problems and solving them. It means that roles of the significant persons in each system are formed to accept and integrate knowledge and information from those in other systems. It means that there is a single, integrated support system for the child.

If we view as isolated incidents the events that have transpired over the past several years with regard to the treatment of hyperactive children, then the creation of solutions is valuable only to insure that children being treated currently, and those who may be treated for hyperactivity in the future, will be assured of the best that can be done for them. Reflection on our data leads us to believe that, even given the limitation in technical knowledge, we are not treating the hyperactive children as well as we could. We believe that additional and more potent psychopharmacological techniques for children and adolescents will be developed. When one recognizes that psychopharmacological technology has not reached its culmination with the development of this generation of existing drugs, one sees that our need to think carefully and to create the policy and social forms needed to apply to this technology sensibly is well worth the effort.

Policy Implementations

This report is the culmination of years of research on hyperactivity. Much like the hackneyed call for additional research which is a standard part of the last chapter of every doctoral dissertation, we have included a call for policy in many of the papers we have written on the topic. Our call for policy, however, is not a mindless pronouncement, but rather reflects our conclusion, based on our research, that the well-being of children requires thoughtfully constructed policy. If policy came when called, like a well-trained dog, we would have long since had public policy for this health problem.

As we have reflected on the meaning of our data, we have considered the problem of developing both permanent and makeshift solutions. The makeshift solutions are important as we respond to the teacher or to the parent who is anxious about what they can do for their hyperactive child or pupil. How, given the world as it presents itself to them, can they provide help? A parent of a hyperactive child is understandably disturbed by solutions that require fairly extensive social change and a lengthy period of time to implement. The permanent solution to the problems we have identified in this research, however, can be achieved only through social change. Changes in the ways in which persons see their own and other roles is essential for the requisite improvements.

Policy is a prescription for behavior formally sanctioned by an organization. The relationship between policy and role as we have used it is clear. The need is to change perspective. Policy provides a behavioral basis for such a change of perspective.

In chapter one we mentioned some volatile experiences growing out of the problem of treating hyperactive children. We have suggested that this is a reason for policy to be formed. Others read it quite differently. For them, these volatile occurrences suggest that policy should not be formed. The principle involved here is an old and venerable one: let sleeping dogs lie. To begin the task of policy formation is inevitably to call attention to what might be a hidden problem within the confines of the school district or community. When attempts are made to convene the persons involved and initiate activities that lead toward policy, attention is called to the situation and can conceivably result in a volatile confirmation.

In the face of this controversy, the question arises about whether policy is to be made concerning hyperactivity and its treatment, or the controversy about hyperactivity and its treatment. The hopeless entwining of these two questions frequently creates an impasse which the attempt to develop policy does not survive. There are two independent inhibitors of policy formation. The first is the pro- and anti-hyperactivity and its treatment controversy. The second is the difference in opinion about the need for policy. Some who are in favor of diagnosing and treating hyperactive children reject the need for policy for reasons just described; others oppose specific policies because of substantive disagreements.

There is another consideration which we think is very important in understanding the constraints on policy formation. Several different types of persons must be involved if policy for screening, diagnosis, and treatment of hyperactive children is to be formed. If policy is to help us determine when it is appropriate for children to be sent for medical consultation and when not, and so on, then it is necessary that a variety of persons be consulted. Parents, physicians, educational personnel--all have some involvement in these activities and thus their participation is required.

We know that when there are different beliefs and attitudes among these individuals about what should and should not be done, we confront a very difficult task in trying to achieve some measure of agreement. Yet this might not seem, at first consideration, to differ from the task before any group that sits down to confront some issue when there are alternative positions possible. The important features, in the case of the policy pertaining to hyperactive children, are that the perspectives and beliefs that are brought to this problem are wedded to social system membership.

From the perspective of the medical social system, the hyperactive child represents a medical problem to be coped with. From the perspective of the educational social system, the child represents a learning and behavior problem. From the perspective of the familial social system, the hyperactive child represents a day-to-day behavior problem; an enduring and agonizing question is whether the child can meet the total array of social expectations that are required for successful functioning within the society. Even though the behavioral deficits of hyperactivity transcend any one system, it is viewed by different system members from the perspective of the goals and natures of their own systems. Therefore, the meaning of technology is segmented. What is confronted here in the formulation of policy are not random differences but rather systematic differences in the perspective of differently structured, differently functioning social systems with oftentimes competing definitions of the situation, goals, function, and legitimacy.

What are the implications of this for policy formation, when several individuals sit around a table attempting to figure out what should be done and how rules for behavior should be fashioned? They confront the issue not only as individuals representing a particular point of view which may be arbitrated and negotiated, but also in a very real sense as representatives and guardians of the perspective of their system. While the propensity to serve as guardians may vary from individual to individual, it is unlikely that a physician, parent, or teacher will ever totally relinquish their role as a physician, parent, or teacher. The extent of flexibility possible in the negotiations and discussion, and the extent of the articulation of perspectives that would lead to a coherent social policy, will probably inevitably be constrained by the social system membership.

This divergence of expected behavior, attitude, and perspective of members of various social systems has, for the hyperactive child, been documented quite strongly in our own data. Our data indicate that parents, teachers, and physicians disagree on attitudes toward psychoactive medication, on the perspective of the assignment of etiology to the condition, its nature and characteristics, and the degree to which the same set of behaviors is expected of one another.

We have never ceased to be both intrigued and dismayed by the realization that, when looked at in this multi-system perspective, it becomes apparent that policy is most needed by the persons who are the least powerful members of the systems, which is to say, the children and their parents. Over the last several years we have had the opportunity to speak to many different groups. We have spoken to groups of teachers, school administrators, physicians, and to parents of hyperactive children. It has been our experience that the most receptive audiences for the notion of need for policy have been those composed of parents of hyperactive children. We have felt a different kind of affective response to the message. While, in many instances, teachers and physicians support the need for policy formation, one senses an immediacy and an urgency on the part of parents of hyperactive children to grasp this message and frequently the response is "of course this is needed but how do I go about accomplishing it? How do I get my school system or my doctor to do this?" The response is that, as a member of the familial system, the parent cannot accomplish this. The lack of power of the parent frequently results in the parent and child being subject to a chaotic, uncertain, and unsatisfactory natural history of identification and treatment that is in itself severely systematic of a lack of coherent policy. The lack of impact that the parents have on the medical and educational system, as the most urgent petitioners for policy, means that the best that many can do is to compose an ad hoc orchestration of resources to attempt to cope with a single child's difficulties in the system. It seems to us that understanding the manner in which many of the difficulties we confront are rooted in social system membership and in beliefs, attitudes, and conceptions which are not random and unsystematic does not mean that we are doomed continuously to relive this problem. Rather, it appears that our analyses, if applied, may provide an ability to generate insights about inertia, the controversy, and social forces which hamper true development of policy.

References

- Arnold, L. E. Detection and management of hyperkinetic children in school. School Counselor, January 1971, 18, 177-184.
- Arnold, L. E. Causes of hyperactivity and implications for prevention. School Psychology Digest, February 1976, 5, 4.
- Biddle, J. & Thomas, E. Role theory concepts and research. New York: John Wiley & Sons, 1966.
- Bosco, J. J. & Robin, S. S. Ritalin usage: a challenge to teacher education. Peabody Journal of Education, 1976, 53, 187-193.
- Bosco, J. J. & Robin, S. S. (Eds.) The hyperactive child and stimulant drugs: definitions, diagnosis and directives. Chicago and London: The University of Chicago Press, 1977.
- Bruck, C. Battle lines in the Ritalin war. Human Behavior, August 1976.
- Cantwell, D. P. Familial-genetic research with hyperactive children. In D. P. Cantwell (Ed.), The hyperactive child: diagnosis, management, current research. New York: Spectrum, 1975(b).
- Cauffman, J. G., Warburton, E. A. & Shultz, C. S. Health care of school children: effective referral patterns. American Journal of Public Health, 1969, 59, 86-91.
- Charles, A. Drugs for hyperactive children: the case of Ritalin. The New Republic, October 1971.
- Clement, W. Solursh, L. & VanAst, W. Abuse of amphetamine and amphetamine-like drugs. Psychological Reports, 1970, 26, 343-354.
- Clinical Global Impressions (MH9-28173). From E.C.D.E.U. Assessment Manual for Psychopharmacology, N.I.M.N., A.D.M.A., 1973.
- Cole, S. Hyperkinetic children: the use of stimulant drugs evaluated. American Journal of Orthopsychiatry, 1975, 75(1).
- Conners, C. K. Rating scales for use in drug studies with children. Psychopharmacology Bulletin, (Special issue: Pharmacotherapy for children), 1973, 24-84.(c)
- Conners, C. & Eisenberg, L. The effects of methylphenidate on symptomatology and learning in disturbed children. American Journal of Psychiatry, 1963, 120, 458-464.
- Conrad, P. The discovery of hyperkinesis: rules on the medicalization of deviant behavior. Social Problems, 1975, 23, 13-21.

- Conway, A. An evaluation of drugs in the elementary schools: some geographic considerations. Journal of Psychology in the Schools, 1976, 13, 442-444.
- Divoky, D. Toward a nation of sedated children. Learning, 1973, 7-13.
- DSM III Diagnostic and statistical manual. Published by American Psychiatric Association, 1980.
- Duncan, O. A socioeconomic index for all occupations. In A. Reiss, Jr., et al., Occupations and social status. Glencoe: Free Press, 1961.
- Eisenberg, L. Principles of drug therapy in child psychiatry with special reference to stimulant drugs. American Journal of Orthopsychiatry, 1971, 41(3).
- Eisenberg, L. The clinical use of stimulant drugs in children. Pediatrics, May 1972, 49, 5.
- Epstein, L. C. Chemctherapy and the hyperkinetic child. Journal of Education, December 1968, 151, 47-60.
- Freeman, R. Drug effects on learning in children: a selective review of the past thirty years. The Journal of Special Education, 1966, 1(1), 7-44.
- Gallagher, C. E. Federal involvement in the use of behavior modification drugs on grammar school children (Hearing before a subcommittee of the Committee of Government Operations, House of Representatives, September 29, 1970). Washington, D. C.: U.S. Government Printing Office, 1970.
- Gittelman-Klein, R., Spitzer, R. L. & Cantwell, D. P. Diagnostic classifications and psychopharmacological indications. In J. S. Werry (Ed.), Pediatric psychopharmacology: The use of behavior modifying drugs in children. New York: Brunner/Mazel, 1978
- Glennon, L. A. & Nason, D. C. Managing the behavior of the hyperkinetic child: what research says. Reading Teacher, 1974, 27, 815-824.
- Glock, C. Y. & Stark, R. Christian beliefs and anti-semitism. New York: Harper & Row, 1966.
- Greenberg, L. M. & Lipman, R. S. Pharmacotherapy of hyperactive children: current practices. Clinical Proceedings, Children's Hospital, 1971, 27, 101-105.
- Gross, N., Mason, W. & McEachern, A. Explorations in role analysis studies of the superintendency role. New York: John Wiley & Sons, 1957.
- Hambrick, D. Is medicine a "crutch?" The Dispatch, June 1974(a).

- Hambrick, D. Too many pupils are on medicine. The Dispatch, 1974(b).
- Harlin, V. K. Help for the hyperactive child in school. Journal of School Health, December 1972, XLII.
- Hills, S. Drugs and the medicalization of human problems. Journal of Drug Education, 1977, 7, 4.
- Homan, G. The human group. New York: Harcourt Brace and World, 1950.
- Homan, G. Human behavior: its elementary forms. New York: Harcourt Brace and World, 1961.
- Huessy, H. R. Study of the prevalence and therapy of the choreati-form syndrome or hyperkinesis in rural Vermont. Acta Paedopsychiatrica, 1967, 34, 130-135.
- Huessy, H. R. Hyperkinetic problems continue to teens. Clinical Psychiatry News, 1974, 2, 5.
- Huessy, H. R. & Gendron, R. M. Prevalence of the so-called hyperkinetic syndrome in public school children of Vermont. Acta Paedopsychiatrica, 1970, 37, 243-248.
- Huessy, H., Marshall, C. D. & Gendron, G. A. Five hundred children followed from Grade 2 through grade 5 for the prevalence of behavior disorder. Acta Paedopsychiatrica, 1973, 39, 301-309.
- Interagency Collaborative Group on Hyperkinesis. 1975 proceedings of 9-30-75 meeting of Interagency Collaborative Group on Hyperkinesis. H.E.W., Washington, D.C.
- Jackson, J. A. Role. Cambridge: Cambridge University Press, 1972.
- Juliano, D. B. Conceptual tempo, activity, and concept learning in hyperactive and normal children. Journal of Abnormal Psychology, 1974, 83, 629-634.
- Keogh, B. Hyperactivity and learning disorders: review and speculation. Exceptional Children, 1971, 38, 101-110.
- Knobel, M. Psychopharmacology for the hyperkinetic child. Archives of General Psychology, Jan.-June, 1962, 6, 198-202.
- Krager, J. & Safer, D. J. Type and prevalence of medication used in the treatment of hyperactive children. New England Journal of Medicine, November 21, 1974.
- Krech, D. Controlling the mind controllers. The Education Digest, December 1966, 32, 1-4.
- Kuhn, A. The logic of social systems. Washington: Josey-Bass, 1974.

- Ladd, E. T. Pills for classroom peace. Saturday Review, November, 1970, 53, 66-83.
- Lambert, N., Sandoval, J. H. & Sassone, D. M. Multiple prevalence estimates of hyperactivity in school children and the rate of occurrence of treatment regimens. National Institute of Mental Health Grant No. ROL MH 20756-010-4, Hyperkinetic Behavior Syndrome Workshop, June 15-16 1978, Washington, D.C.
- Lapouse, R. & Monk, M. A. An epidemiologic study of behavior characteristics in children. Behavior Characteristics of Children, September 1958, 48(9).
- Laufer, M. Long-term management and some follow-up findings on the use of drugs with minimal cerebral syndromes. Journal of Learning Disabilities, November 1971, 4(9), 518-522.
- Loney, J. Parental management, self-concept, and drug response in minimal brain dysfunction. Journal of Learning Disabilities, March 1975, 8(3).
- Loomis, C. P. & Loomis, Z. K. Modern social theories, Princeton: D. VanNostrand Co., Inc., 1961
- Miller, R. G., Palkes, H. S. & Stewart, M. A. Hyperactive children in suburban elementary schools. Child Psychiatry and Human Development, 1973, 4(2).
- Millichap, J. Drugs in management of hyperkinetic and perceptually handicapped children. JAMA, November 11, 1968, 206(7), 1527-1530.
- Monane, J. H. A sociology of human systems. New York: Appleton Century Crofts, 1967.
- Murray, J. Drugs to control classroom behavior? Educational Leadership, 1973, 31, N1, 21-25.
- Oettinger, L., Jr. Rehabilitation literature, learning disorders, hyperkinesis, and the use of drugs in children. Rehabilitation Literature, June 1971 32, 161-167, 170.
- Office of Child Development. Report on the conference on the use of stimulant drugs in the treatment of behaviorally disturbed young school children. Washington, D.C.: Department of Health, Education and Welfare, 1971.
- Offir, C. A slavish reliance on drugs: are we pushers for our own children? Psychology Today, December 1974.
- Parsons, T. Age and sex in the social structure of the United States. American Sociological Review, 1942, 7, 604-616.
- Parsons, T. The social system. New York: Free Press, 1951.

- Parsons, T. An outline of the social system. In T. Parsons, E. Shils, K. Naegle and J. Pitts (Eds.), Theories of society, Glencoe: Free Press, 1961.
- Renshaw, D. C. The hyperactive child. Chicago: Nelson-Hall, 1974.
- Robin, S. Three approaches to role theory. In O. Callahan and M. Levine (Eds.), Theories and practicums in contemporary sociology. New York: F. E. Peacock Publishers, 1964.
- Robin, S. S. & Bosco, J. J. Ritalin for school children: the teacher's perspective. The Journal of School Health, December 1973, XLIII(10), 624-628
- Robin, S. S. & Bosco, J. J. Three perspectives on the use of Ritalin: teachers, prospective teachers and professors, II. An examination of problems in attitude formation and professional practice. Paper presented to Council for Exceptional Children, New York, April 1974.
- Robin, S. S. & Bosco, J. J. An analysis of Coleman's desegregation research and policy recommendations. School Review, May 1976, 84.
- Robin, S. S. & Bosco, J. J. The social context of stimulant drug treatment for hyperkinetic children. In James J. Bosco and Stanley S. Robin (Eds.), The hyperactive child and stimulant drugs. Chicago and London: The University of Chicago Press, 1977, 141-153.
- Rosenberg, M. & Simmons, R. Black and white self-esteem: the urban shool child. The American Sociological Association, 1972. Washington, D. C.
- Ross, D. M. & Ross, S. A. Hyperactivity - research, theory and action. New York: John Wiley & Sons, 1976.
- Sandoval, J., Lambert N. M. & Sassone, D. The identification and labeling of hyperactivity in children: an interactive model. In Carol K. Whalen & Barbara Henker (Eds.), Hyperactive children: the social ecology of identification and treatment. New York: Academic Press, Inc., 1980.
- Schuckit, M. A., Petrich, J. & Chiles, J. Hyperactivity: diagnostic confusion. Journal of Nerv. Ment. Disorders, 1978, 66, 79-87.
- Scoville, B. Symposium: stimulant drugs and the schools: dimensions in the remediation of social toxicity. III. Government perspectives in the evaluation and regulation of stimulant drugs for hyperkinetic children. Paper presented at the annual meeting of the Council for Exceptional Children, New York, April 1974.

- Silver, L. A proposed view on the etiology of the neurological learning disability syndrome. Journal of Learning Disabilities, 1971, 4, 123-133.
- Sprague, R. Methylphenidate in hyperkinetic children: differences in dose effects on learning and social behavior. Science, 1977, 198, 1274-1276.
- Sprague, R., Barnes, K. R. & Werry, J. S. Methylphenidate and thioridazine: learning, reaction time, activity and classroom behavior in disturbed children. American Journal of Orthopsychiatry, July 1970, 615-628
- Sprague, R. L. & Gadow, K. D. The role of the teacher in drug treatment. In James J. Bosco & Stanley S. Robin (Eds.) The hyperactive child and stimulant drugs. Chicago: University of Chicago Press, 1977.
- Sprague, R. L. & Sleator, E. K. Effects of psychopharmacological agents on learning disabilities. Pediatric Clinics of North America, 1973, 20, 719-735.
- Staff Report. Hyperkinesis control in elementary schools. Education Committee of the California State Senate, 1974.
- Stewart, A., Pitts, F. N., Craig, G. & Dieruf, W. The hyperactive child syndrome. American Journal of Orthopsychiatry, October 1966, 36(5), 861-867.
- Swazey, J. Myths, muckraking, and hyperactive children. Hastings Center Report, April 1976.
- Time Magazine. Classroom pushers. Time, February 26, 1973, 65.
- Vinnedge, H. Politicians who would practice medicine: drugs for children. The New Republic, March 1971.
- VonderHaar, T. Chaining children with chemicals. The Progressive, 1975, 39, 3, 13-17.
- Weiss, G., Minde, K., Werry, J., Douglas, V. & Nemeth, E. Studies on the hyperactive child. Archives of General Psychiatry, May 1971, 24, 409-414.
- Wells, W. Drug control of school children: the child's right to choose. Southern California Law Review, 1973, 46, 585-616.
- Welsh, E. You may not know it, but your schools probably are deeply into the potentially dangerous business of teaching with drugs. The American School Board Journal, February 1974, 161, #2, 41-45.
- Wender, P. H. Minimal brain dysfunction in children. New York: Wiley, 1971.

- Werner, E., Bierman, J. M., French, F. E., Simonian, K., Connor, A., Smith, R. & Campbell, M. Reproductive and environmental casualties: a report of the 10-year follow-up of the children of the Kauai pregnancy study. Pediatrics, July 1968, 42, No. 1. 112-127.
- Whalen, C. K. & Henker, B. Psychostimulants and children: a review and analysis. Psychological Bulletin, 1976, 83, 1113-1130.
- Whalen, C. K. & Henker B. The pitfalls of politicization: a response to Conrad's "The discovery of hyperkinasis: notes of the medicalization of deviant behavior." Social Problems, June 1977, 24(5), 590-595
- Whalen, C. K. & Henker, B. The social ecology of psychostimulant treatment: a model for conceptual and empirical analysis. In Carol K. Whalen & Barbara Henker, (Eds.) Hyperactive children: the social ecology of identification and treatment. New York: Academic Press, 1980.
- Williams, R. American society (2nd ed.). New York: Alfred A. Knopf, Inc., 1960.
- Witter, C. Drugging and schooling. Transaction, August 1971, 8, #9/10, 30-34.

Appendix A

Instruments

INSTRUMENTS

MAILED QUESTIONNAIRES:

QUESTIONNAIRE: Parents
 QUESTIONNAIRE: Teachers

INTERVIEW SCHEDULES:*

BACKGROUND: Parents
 BACKGROUND: Physicians
 BACKGROUND: Teachers
 BACKGROUND: Child
 EVENTS, PROCESS AND ROLE BEHAVIOR: Parents
 EVENTS, PROCESS AND ROLE BEHAVIOR: Physicians
 EVENTS, PROCESS AND ROLE BEHAVIOR: Teachers
 EVENTS, PROCESS AND ROLE BEHAVIOR: Child
 ASSESSMENT: Parents
 ASSESSMENT: Physicians
 ASSESSMENT: Teachers
 ASSESSMENT: Child
 ROLE: Parents, Physicians, Teachers
 ATTITUDE GENERAL: Parents
 ATTITUDE GENERAL: Physicians
 ATTITUDE GENERAL: Teachers
 ATTITUDE GENERAL: Child
 SPECIFIC BELIEFS: Parents
 SPECIFIC BELIEFS: Physicians
 SPECIFIC BELIEFS: Teachers
 AWARENESS OF MEDICATION: Child
 PROCEDURE IN TAKING MEDICATION: Child
 RESPONSES OF OTHERS TO CHILD: Child
 SELF-ESTEEM: Child

*Rather than including all interview schedules for all phases (initiation, monitoring and termination) in their entirety, the above is an index of the sections included in the various interview schedules. Within each section will be found all of the questions comprising that section, with additional pages denoting changes within a particular section, when applicable, for monitoring and termination phases.

MAILED QUESTIONNAIRES

SCHOOL CHILD SURVEY

1. Please list the ages of your children and indicate ☒ their sex. Include all children who were members of your household, even if they now are grown and live elsewhere. (Continue on back if necessary.)

First Name	Age	Male	Female
1. _____	_____	☐	☐
2. _____	_____	☐	☐
3. _____	_____	☐	☐
4. _____	_____	☐	☐
5. _____	_____	☐	☐

2. This questionnaire is being answered by:

father ☐ stepfather ☐ male guardian ☐ female guardian ☐
 mother ☐ stepmother ☐ other (please specify) _____

3. In what age category are you?

20-24 ☐ 25-29 ☐ 30-34 ☐ 35-39 ☐
 40-44 ☐ 45-49 ☐ 50-54 ☐ 55 or older ☐

4. In what age category is your spouse—if you have one?

20-24 ☐ 25-29 ☐ 30-34 ☐ 35-39 ☐
 40-44 ☐ 45-49 ☐ 50-54 ☐ 55 or older ☐

5. What is the occupation of the father (stepfather, male guardian)—such as lawyer, auto mechanic, salesman—in your family? _____

6. What is the occupation of the mother (stepmother, female guardian)—such as lawyer, auto mechanic, salesman—in your family? _____

PLEASE ANSWER THE REST
OF THE QUESTIONS ABOUT
THIS CHILD

7. Has your child had a medical diagnosis of a learning or behavior problem?

Yes ☐ No ☐

What was this diagnosis? _____

Who made the diagnosis? Physician ☐ Teacher ☐ Counselor ☐ Nurse ☐

Psychologist ☐ Other person ☐ (specify) _____

8. Please check any of the following diagnoses that have been made for your child.

- | | | | | | |
|--------------|--------------------------|---------------------|--------------------------|--------------------------------------|--------------------------|
| MBD | ☐ | Overactive | ☐ | Minimal brain dysfunction | ☐ |
| Hyperkinesis | ☐ | Impulse disorder | ☐ | Minimal cerebral dysfunction | ☐ |
| Hyperkinetic | ☐ | Learning disorder | ☐ | Hyperkinetic Child Behavior Syndrome | ☐ |
| Hyperactive | ☐ | Learning disability | ☐ | | |

My child has not been diagnosed in any of these ways ☐

9. Is—or has—your child been treated in any of the following ways?

	Yes this treatment is—or has— been used	Treatment started month/year	If treatment has been ended, when did it end?
	☒		
Megavitamin therapy	☐	_____	_____
Counseling	☐	_____	_____
Special Diet	☐	_____	_____
Behavior Modification	☐	_____	_____
Psychiatric Treatment	☐	_____	_____
Medication for some sort of behavior or learning problem	☐	_____	_____
If your child is taking or has taken medication check below:			
Dextroamphetamine (Dexadrine)	☐	_____	_____
Mellaril	☐	_____	_____
Dilantin	☐	_____	_____
Cylert	☐	_____	_____
Phenobarbital	☐	_____	_____
Ritalin	☐	_____	_____
Benadryl	☐	_____	_____
Valium	☐	_____	_____
Imprimine (Tofranil)	☐	_____	_____
Coffee or Tea (Caffeine)	☐	_____	_____
Other _____	☐	_____	_____

10. If you are not sure what your child is taking, please look at the label of his medication and copy it here. _____
11. Listed below are items concerning children's behavior or the problems they sometimes have. Read each item carefully and decide how much you think this child has been bothered by this problem at this time: NOT AT ALL, JUST A LITTLE, PRETTY MUCH, or VERY MUCH. Indicate your choice by checking the box ☒ in the appropriate column to the right. Please answer all items.

	Not at All	Just a Little	Pretty Much	Very Much
1. Restless	☐	☐	☐	☐
2. Excitable, impulsive	☐	☐	☐	☐
3. Disturbs other children	☐	☐	☐	☐
4. Fails to finish things he starts (short attention span)	☐	☐	☐	☐
5. Fidgeting	☐	☐	☐	☐
6. Inattentive, distractable	☐	☐	☐	☐
7. Demands must be met immediately; easily frustrated	☐	☐	☐	☐
8. Cries	☐	☐	☐	☐
9. Mood changes quickly	☐	☐	☐	☐
10. Temper outbursts (explosive and unpredictable behavior)	☐	☐	☐	☐

If you checked "pretty much" or "very much" for any of the above items, please indicate where these behaviors usually occur:

at school ☐

everywhere ☐

at home ☐

other (please specify) _____

1. How many children are enrolled in your class at the present time? (For Middle/Junior High School teachers, "your class" refers to your home room class.) _____
2. What grade level(s) are you teaching? _____
3. How many children in your class this year do you believe exhibit symptoms of the condition known as the hyperkinetic (hyperactive) child behavior pattern? _____
4. How many children in your class this year do you know of **who have been diagnosed by a physician** as **any** of the following: hyperkinetic, hyperactive, learning disorder, learning disability, overactive, as having hyperkinesis, minimal brain dysfunction, MBD, impulse disorder, hyperkinetic child behavior syndrome, minimal cerebral dysfunction? _____
5. Please indicate the number of children in your class this year who are being treated or who were being treated at any time this school year in the following ways. A child may be counted more than once if treated in more than one way.

Treatment	Number of Children	Treatment	Number of Children
a. Megavitamin Therapy	_____	e. Behavior Modification	_____
b. Counseling	_____	f. Psychiatric Treatment	_____
c. Special Diet	_____	g. Medication for Behavioral	_____
d. Remedial Instruction	_____	or Learning Problems	_____

6. If there are children in your classroom this year being treated with medication(s) for behavioral or learning problems (question 5g above), please indicate how many children are being treated with each of the following medications:

Medication	Number of Children	Medication	Number of Children
Dextroamphetamine (Dexadrine)	_____	Benadryl	_____
Mellaril	_____	Valium	_____
Dilantin	_____	Imprimine (Tofranil)	_____
Cylert	_____	Coffee or Tea (Caffeine)	_____
Phenobarbital	_____	Other (please specify)	_____
Ritalin	_____	Unknown	_____

7. What is the name of the school you teach in? _____

BACKGROUND

BACKGROUND: Parents

1. Would you tell me your full name? _____
2. What is your husband's (or wife's) first name? _____
- (TURN ON RECORDER HERE IF PERMISSION WAS GRANTED.)
3. What is your relationship to (child's name)? _____
4. What is the name of the doctor who treats (child's name) for hyperactivity?

5. What was the name of (child's name) teacher when he/she began medication treatment? _____
6. At what school does this teacher teach? _____
7. How many years have you lived in Grand Rapids? _____

BACKGROUND: Physicians

1. Sex: Male _____ Female _____

2. What is the approximate age characteristics of your practice? Could you tell me if the:

Majority of your patients are adult, _____

Majority of your patients are adult or adolescent, or; _____

Majority of your patients are children under 13. _____

3. For how many years have you been a practicing physician? _____

4. Could you tell me your age? _____

5. Could you estimate what proportion of your patients are being treated by you for hyperkinesis?

Very few (1 - 2%) _____

A small proportion (3 - 5%) _____

A substantial proportion (6 - 25%) _____

I specialize in treating these conditions. _____

6. Are patients with school and behavioral problems referred to you by other physicians?

Yes _____

No _____

BACKGROUND: Teachers

1. You now teach _____ level (grade).

2. Have you ever taught in another level? Yes _____ No _____

2a. (IF YES) What level? _____ How many years? _____

Level	Number of Years
K _____	_____
1 _____	_____
2 _____	_____
3 _____	_____
4 _____	_____
5 _____	_____
6 _____	_____
7 _____	_____
8 _____	_____
9-12 _____	_____

3. How many years have you taught? _____

4. How many years have you been teaching in Grand Rapids Public schools? _____

5. Have you ever been a special education teacher? Yes _____ No _____

5a. (IF YES) What type of special education instruction were you involved in?

5b. (IF YES) For how many years? _____

6. In all your years as a teacher approximately how many hyperactive children in your classes have taken medication for this condition? _____

7. Have you had any course work, training or inservice dealing with hyperactive children and/or their treatment? Yes _____ No _____ Don't remember _____

7a. (IF YES) What was it? _____

Interviewer: Hello I am Mrs. (Miss) _____. Are you (child's first name)? I would like to talk to you for a little while and ask you some questions about yourself. I would like to record our talk with this tape recorder so I can be sure to get everything you say right. If you like, we can listen to a little of this on the tape recorder after we're done. Is it OK with you if we use the tape recorder? (IF CHILD SAYS NO TURN IT OFF, PUT IT AWAY AND PROCEED WITH INTERVIEW).

1. What is the name of your teacher? _____
2. Do you have any brothers or sisters?
Yes _____ No _____
3. How old are you? _____
4. What do you like to do best in school? _____

(NOTE DIFFERENCE BETWEEN PROBES AND FOLLOW-UP QUESTIONS. PROBES ARE USED ONLY IF THE SUBJECT CAN NOT RESPOND TO THE INITIAL QUESTION. FOLLOW-UP QUESTIONS ARE TO BE USED WHEN IT IS NECESSARY TO FOLLOW A PARTICULAR RESPONSE AND ANSWER WITH ANOTHER QUESTION. THE FOLLOW-UP QUESTION WILL BE SIGNALLED BY THE DIRECTIONS "IF YES" OR "IF NO.")

EVENTS, PROCESS AND ROLE BEHAVIOR

EVENTS, PROCESS AND ROLE BEHAVIOR: Parents

What I would like to do now is get some background information about how (child's name) came to be diagnosed as hyperactive and treated with medication. I am going to ask you some questions. Your answers to these questions will give us a picture of (child's name) diagnosis and treatment.

(PROBLEM RECOGNITION AND RESPONSE)

1. Who first brought up the idea that (child's name) had a learning or behavior problem?

child's mother _____
 child's father _____
 relative _____
 child's teacher _____
 child's doctor _____
 other (specify) _____
 don't know _____
 don't remember _____

- 1a. (IF OTHER THAN MOTHER OR FATHER) How did you hear about the child's problem?

2. What problems was (child's name) thought to be having at that time?

3. When was this? Month _____ Year _____

4. Did either you or your spouse suspect any problem before this time?

Yes _____ No _____ Don't remember _____

5. Who first brought up the idea that (child's name) needed professional help because of his/her problem?

child's mother _____
 child's father _____
 relative _____
 child's teacher _____
 child's doctor _____
 other (specify) _____
 don't know _____
 don't remember _____

6. Who first brought up the idea that (child's name) needed medical help?

child's mother _____
 child's father _____
 relative _____
 child's teacher _____
 child's doctor _____
 other (specify) _____
 don't know _____
 don't remember _____

*7. In addition to (child's name) doctor, did you or your spouse go to anyone for help?

Yes _____ No _____ Don't remember _____

7a. (IF YES) Specify _____

(DIAGNOSIS)

8. Were you informed of (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

8a. (IF YES) From whom?

doctor _____	school social worker _____
doctor's nurse _____	school nurse _____
teacher _____	school psychologist _____
other (specify) _____	

8b. What was the diagnosis? (IF RESPONDENT DOES NOT UNDERSTAND THE QUESTION, ASK: WHAT WAS THE MEDICAL TERM[S] THAT WAS USED TO DESCRIBE THE CHILD'S CONDITION?)

*9. Did you talk with the doctor about the details and meaning of (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

9a. (IF YES) Do you feel your talk with the doctor enabled you to understand (child's name) condition?

Yes _____ No _____

9b. (IF YES) What, if anything, did you find out that was helpful and important for you to know?

9c. (IF YES) What questions or concerns, if any, did you have that were not answered by the doctor when you talked with the doctor about the meaning of (child's name) diagnosis?

10. When was the diagnosis made?

Month _____ Year _____ Don't remember _____

11. How long (approximate number of minutes) was the doctor's visit during which the diagnosis was made? _____

*12. Did you talk to the doctor about (child's name) behavior at home?

Yes _____ No _____ Don't remember _____

*13. Did you suggest to the doctor that (child's name) might be hyperactive before the doctor made the diagnosis?

Yes _____ No _____ Don't remember _____

*14. Did you explain (child's name) diagnosis to other members of the family who were old enough to understand?

Yes _____ No _____ Don't remember _____

*15. Did you tell members of the school system about (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

15a. (IF YES) Whom in school did you tell about (child's name) diagnosis?

principal _____	physical education teacher _____
school nurse _____	reading teacher _____
school social worker _____	teacher aides _____
school psychologist _____	other (specify) _____
child's teacher _____	

- *16. Did you talk with the teacher or any other member of the school system about the details and meaning of (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

- 16a. (IF YES) Do you feel that your discussion about (child's name) diagnosis helped the teacher or other members of the school system do a better job in the classroom dealing with (child's name) hyperactive condition?

Yes _____ No _____ Don't know _____

- 16b. (IF YES) Do you feel that your discussion with the teacher (or other school personnel) helped you to understand more about (child's name) condition or his/her school situation?

Yes _____ No _____ Don't know _____

- *17. Did you discuss the details and meaning of (child's name) diagnosis with (child's name)?

Yes _____ No _____ Don't remember _____

18. When (child's name) was being diagnosed, did you request consultation with one or more specialists in addition to your doctor?

Yes _____ No _____ Don't remember _____

(MEDICATION TREATMENT)

19. When was the decision to place the child on medication made?

Month _____ Year _____ Don't remember _____

- *20. Did you recommend the use of medication?

Yes _____ No _____ Don't remember _____

- 20a. (IF YES) Was it a specific medication?

Yes _____ No _____

- 20b. (IF YES) What was it? _____

21. Whose decision was it to use medication treatment for (child's name)?
(CHECK MORE THAN ONE RESPONSE IF THE DECISION IS SEEN AS A JOINT DECISION.)

teacher _____
parent _____
doctor _____
other (specify) _____

- *22. Did you explain to the household members old enough to understand why (child's name) is taking medication?

Yes _____ No _____ Don't know _____

*23. Did you tell the teacher that (child's name) was being treated with medication?

Yes _____ No _____ Don't remember _____

*24. Did you tell others in the school system that (child's name) was being treated with medication?

Yes _____ No _____ Don't remember _____

24a. (IF YES) Who?

school psychologist _____	school social worker _____
principal _____	reading teacher _____
physical education teacher _____	others (specify) _____
music teacher _____	

25. Were any other means of dealing with (child's name) tried before medication was begun?

Yes _____ No _____ Don't remember _____

25a. (IF YES) What were they?

behavior modification _____	psychiatric treatment _____
special diet _____	counselling _____
changes in classroom situation _____	
other (specify) _____	

26. Has there been any change in the medication treatment of (child's name) since treatment began?

Yes _____ No _____ Don't remember _____

26a. (IF YES) What change was there?

dosage _____	
type of medication _____	
time at which medication was given _____	
other (specify) _____	

*27. Do you give (child's name) one or two pills to take to school each day?

Yes _____ No _____

*28. Do you give (child's name) pill to him/her each time he/she takes it at home?

Yes _____ No _____

28a. (IF NO) Do you know who sees to it that (child's name) takes his/her medicine at home?

Yes _____ No _____

29. Where is the medicine kept at home? _____
- *30. Did you talk to (child's name) about what his/her medication is supposed to do for him/her?
- Yes _____ No _____ Don't remember _____
- *31. Did you, yourself, change the dosage or the times when (child's name) takes his/her medication?
- Yes _____ No _____ Don't remember _____
- 31a. (IF YES) Why? _____
- _____
32. Do you know who sees to it that (child's name) takes his/her medication at school?
- Yes _____ No _____ Don't know _____
- 32a. (IF YES) Who is responsible at school for seeing that (child's name) takes his/her medication?
- classroom teacher _____
- school nurse _____
- principal _____
- other (specify) _____

(ADJUNCTIVE THERAPY)

33. In addition to medication, have any other changes in (child's name) home life or school life been made or other treatments used to help (child's name)?

Yes _____ No _____ Don't know _____

- 33a. (IF YES) What approaches have been or are now being used? (NOTE: YOU NEED NOT READ THE LIST OF APPROACHES. CHECK THOSE MENTIONED BY RESPONDENT AND FOR THOSE MENTIONED, COLLECT THE ADDITIONAL INFORMATION.)

	(Check if Mentioned)	*Was it your idea to try this approach for (child's name)?	When did it Begin - End Dates From To	
Counselling	_____	_____	_____	_____
Megavitamin treatment	_____	_____	_____	_____
Special diet	_____	_____	_____	_____
Changes in your way of reacting to child	_____	_____	_____	_____
Psychiatric treatment	_____	_____	_____	_____
Special education	_____	_____	_____	_____
Changes in home life	_____	_____	_____	_____
Changes in class- room procedures	_____	_____	_____	_____
Counselling for parents	_____	_____	_____	_____
Behavior modi- fication	_____	_____	_____	_____
Other (specify)	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

34. Has (child's name) been treated unfairly by anyone because of his/her diagnosis or treatment?

Yes _____ No _____ Don't know _____

- 34a. (IF YES) By whom?

parents _____	school personnel _____
teachers _____	other children _____
doctor _____	relatives _____
other (specify) _____	

35. Do you think (child's name) might have a better chance for success in school if his/her teachers and other school personnel did not know about his/her diagnosis and treatment?

Yes _____ No _____ Don't know _____

School personnel not informed _____

36. Do you perceive any differences between your own and your spouse's attitude toward treatment?

Yes _____ No _____ Not applicable--no spouse _____

- 36a. (IF YES) What are the differences?

37. Has the fact that (child's name) has been diagnosed as a "hyperactive child" seemed to make some people around him/her blind to (child's name) other qualities?

Yes _____ No _____ Don't know _____

- 37a. (IF YES) Who tends to be this way? _____

38. Do you think (child's name) might be happier at school if others did not know of his/her diagnosis and treatment?

Yes _____ No _____ Don't know _____

School personnel not informed _____

39. Do you think (child's name) might be happier at home if others did not know of his/her diagnosis and treatment?

Yes _____ No _____ Don't know _____

40. Do you think (child's name) benefits at school because school personnel know of his/her diagnosis and treatment?

Yes _____ No _____ Don't know _____

School personnel not informed _____

41. Do you think (child's name) benefits at home because the family knows of his/her diagnosis?

Yes _____ No _____ Don't know _____

(PSYCHOLOGICAL AND SOCIAL SUPPORT)

42. Has the teacher expressed any frustrations or feelings of difficulty about teaching (child's name) to you?

Yes _____ No _____ Don't remember _____

*42a. (IF YES) Have you tried to help her deal with these feelings?

Yes _____ No _____ Don't remember _____

43. Has (child's name) been teased or made fun of because he/she is taking medication?

Yes _____ No _____ Don't know _____

*44. Have you found that (child's name) is being teased at home because of his/her condition or treatment?

Yes _____ No _____ Don't remember _____

*44a. (IF YES) Did you do anything about it?

Yes _____ No _____ Don't know _____

44b. (IF YES) What have you done? _____

*45. Have you found that (child's name) is being teased at school because of his/her condition or treatment?

Yes _____ No _____ Don't know _____

*45a. (IF YES) Did you do anything about it?

Yes _____ No _____ Don't know _____

- 45b. (IF YES) What have you done? _____

46. Do any adults give (child's name) a "hard time" because he/she is taking medication?
Yes _____ No _____ Don't know _____
- 46a. (IF YES) What, if anything, did you do about this?

47. Does (child's name) have personal doubts or bad feelings that stem from the use of medication?
Yes _____ No _____ Don't know _____
- *48. Have you joined or attended meetings of organized groups of parents to discuss problems and hold rap sessions about their hyperactive children?
Yes _____ No _____
- *49. Do you ever get together informally with other parents of hyperactive children to share concerns and information?
Yes _____ No _____ Don't remember _____

EVENTS, PROCESS AND ROLE BEHAVIOR: Parents

The first thing I'd like to do is to get some background information about (child's name) treatment for hyperactivity. I am going to ask you some questions. Your answers to these questions will give us a picture of (child's name) treatment.

(MONITORING)

1. How often do you or your spouse take (child's name) to the doctor to check up for his/her medication? _____
2. When is the last time you took (child's name) in for a check up for the hyperactivity or the medication? (DATE) _____
3. Who usually conducts the check up? _____
4. How do you know when it is time to go to (child's name) doctor for a check up?

The doctor has told me how often I need to go in, i.e. every two months _____
 The doctor contacts me when I need an appointment _____
 I go in to see him each time I need to get a prescription for a refill _____
 I go in when I think it is necessary _____
 Other (specify) _____

- *5. Have you or your spouse had special visits with (child's name) doctor because of problems or difficulties connected with the hyperactivity?
 Yes _____ No _____ Don't remember _____
- 5a. (IF YES) How many of these special visits have you had in the last year? _____
- *6. Do you or your spouse provide the doctor with information to help him evaluate the treatment for (child's name)?
 Yes _____ No _____ Don't know _____
- *7. Do you provide the doctor with information to help him determine if the medication has side effects for (child's name)?
 Yes _____ No _____ Don't know _____
- *8. Do you provide the doctor with information which helps him decide how much medication to give (child's name)?
 Yes _____ No _____ Don't know _____
- *9. Do you provide the teacher with information about (child's name) condition and treatment to help the teacher do a better job in working with (child's name) in the classroom?
 Yes _____ No _____ Don't know _____

- *10. Do you or your spouse serve as a channel of information between teacher and doctor?
 Yes _____ No _____
- 10a. (IF YES) Is the information usually spoken or written?
 Usually spoken _____
 Usually written _____
- *11. Did you get information from other sources (such as school officials, scout leaders, relatives, etc.) about change in (child's name) behavior after medication began?
 Yes _____ No _____
- *12. Have you or your spouse consulted with new teachers at the beginning of the school year to help them relate to and teach (child's name)?
 Yes _____ No _____ Don't remember _____
13. How often do you have a meeting with (child's name) teacher to check up on how things are going with (child's name)?
- Never _____
 Once a year _____
 Couple times a year _____
 Once a month _____
 More than once a month _____
 When teacher calls me in _____
 When I think it's time _____
 When doctor recommends I see the teacher _____
 Other (specify) _____
14. In the past year how many meetings have you had with (child's name) teacher to discuss how things are going? _____
15. When was the last time you met with the teacher?
 Month _____ Year _____
- *16. Have you stopped the medication on a trial basis to see if (child's name) still needs it?
 Yes _____ No _____ Don't remember _____
- *17. Have you suggested to the doctor that medication be discontinued on a trial basis to see if (child's name) still needs it?
 Yes _____ No _____ Don't remember _____
18. Have you requested of the doctor that medication for (child's name) be ended?
 Yes _____ No _____ Don't remember _____

EVENTS, PROCESS AND ROLE BEHAVIOR: Parents

The first thing I'd like to do is get some background information about how (child's name) ended his/her medication treatment for hyperactivity. I am going to ask you some questions. Your answers to these questions will give us a picture of what happened when (child's name) ended treatment.

(TERMINATION)

1. Why was (child's name) medication stopped?

child no longer needed medication _____
 medication doing no good _____
 side effects were too great _____
 child didn't like the idea of medication _____
 parent didn't like the idea of medication _____
 doctor didn't like the idea of medication _____
 teacher didn't like the idea of medication _____
 other (specify) _____

* 2. Did you or your spouse suggest that the medication be ended?

Yes _____ No _____

2a. (IF YES) To whom?

parent _____ doctor _____
 teacher _____ child _____
 other (specify) _____

3. When did (child's name) stop taking the medication?

month _____ year _____

* 4. Did you or your spouse plan for the ending of medication for (child's name) before medication was actually ended?

Yes _____ No _____

* 5. Did you set up a trial ending of medication as a way of finding out if (child's name) medication was no longer needed?

Yes _____ No _____ Don't remember _____

* 6. Did you collect information from the teacher in order to decide whether to stop the medication?

Yes _____ No _____ Don't know _____

6a. (IF YES) What sort of information did you gather?

verbal reports _____
 test results _____
 answers to specific questions asked _____
 written reports _____
 other (specify) _____

- * 7. Did you or your spouse discuss ending medication treatment for (child's name) with his/her teacher?
Yes _____ No _____ Don't remember _____
- * 8. Did you discuss with (child's name) the possibility that medication might no longer be needed?
Yes _____ No _____ Don't remember _____
9. Was medication for (child's name) started again at any time after being stopped?
Yes _____ No _____ Don't remember _____
- * 9a. (IF YES) Did you or your spouse ever recommend to (child's name) doctor that medication be resumed?
Yes _____ No _____ Don't remember _____
10. Did (child's name) have any fears or doubts about stopping the medication?
Yes _____ No _____ Don't know _____
- 10a. (IF YES) Do you know if anyone provided reassurance for (child's name) when he/she ended medication?
Yes _____ No _____ Don't know _____
- 10b. (IF YES) Who? _____
- *11. Did you try to find a time to end medication when (child's name) was not under a lot of pressure? (e.g., during exam time, around Christmas or Spring Holidays, when child is upset about something else)
Yes _____ No _____ Don't know _____

EVENTS, PROCESS AND ROLE BEHAVIOR: Physician

What I would like to do now is get some background information about how (child's name) came to be diagnosed as hyperactive and treated with medication. I am going to ask you some questions. Your answers to these questions will give us a picture of (child's name) diagnosis and treatment.

PROBLEM RECOGNITION AND RESPONSE

1. Who first brought up the idea that (child's name) had a learning or behavior problem?

child's mother _____
 child's father _____
 relative _____
 child's teacher _____
 doctor (self) _____
 doctor (other) _____
 other (specify) _____
 don't know _____
 don't remember _____

- 1a. (IF OTHER THAN SELF) What brought it to your attention?

2. What problems was (child's name) thought to be having at that time?

3. When was this? Month _____ Year _____

4. Did you suspect any problem before this time?

Yes _____ No _____ Don't remember _____

5. Who first brought up the idea that (child's name) needed medical help?

child's mother _____
 child's father _____
 relative _____
 child's teacher _____
 doctor (self) _____
 doctor (other) _____
 other (specify) _____
 don't know _____
 don't remember _____

*6. Did you provide help for the teacher at this pre-diagnostic stage?

Yes _____ No _____ Don't remember _____

*7. Did you provide help for the parents at this pre-diagnostic stage?

Yes _____ No _____ Don't remember _____

7a. (IF YES) What sort of help did you provide for the teacher and/or parents?

DIAGNOSIS

8. What was your initial diagnosis of (child's name) condition?

9. About how long was the visit during which (child's name) was diagnosed?

10. When was this diagnosis made? Month _____ Year _____

11. Has that diagnosis ever been changed? Yes _____ No _____

11a. (IF YES) What is your current diagnosis? _____

11b. (IF YES) When was this diagnosis made? Month _____ Year _____

*12. Did you arrange a consultation with other medical specialists?

Yes _____ No _____ Don't remember _____

*13. Did you talk with the teacher about the child's behavior and learning in school in order to arrive at a diagnosis?

Yes _____ No _____ Don't remember _____

*14. Did you request samples of (child's name) school work, test results, observations, anecdotes or written reports from the teacher to help you make this diagnosis?

Yes _____ No _____ Don't remember _____

*15. Did you actually receive samples of (child's name) school work, test results, observations, anecdotes or written reports from the teacher to help you make this diagnosis?

Yes _____ No _____ Don't remember _____

16. What tests and procedures were used with (child's name) to arrive at a diagnosis? _____
- _____
- _____

- *17. Did you provide the parents with a working knowledge of (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

- *18. Did you provide the teacher with a working knowledge of (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

- *19. Did you explain the nature of his/her condition to (child's name)?

Yes _____ No _____ Don't remember _____

20. Do you feel that (child's name) teacher or other school personnel helped in arriving at your diagnosis? Yes _____ No _____

- 20a. (IF YES) Was the teacher the first to provide the diagnostic label in (child's name) case?

Yes _____ No _____ Don't remember _____

21. Do you feel that (child's name) parent helped in formulating your diagnosis?

Yes _____ No _____ Don't remember _____

- 21a. Was the parent the first person to provide the diagnostic label in (child's name) case?

Yes _____ No _____ Don't remember _____

MEDICATION TREATMENT

22. When was the decision to place the child on medication made?

Month _____ Year _____

- *23. Was there any predisposition on the part of any other adult in (child's name) life to treat him/her with medication?

Yes _____ No _____ Don't remember _____

23a. (IF YES) Who?

mother _____

father _____

teacher _____

other (specify) _____

*24. Did you tell the teacher (child's name) was being treated with medication?

Yes _____ No _____ Don't remember _____

*25. Did you tell others in the school system that (child's name) was being treated with medication?

Yes _____ No _____ Don't remember _____

25a. (IF YES) Who?

school psychologist _____

principal _____

physical education teacher _____

music or reading teacher _____

school social worker _____

reading teacher _____

others (please specify) _____

26. Were any other means of dealing with (child's name) tried before medication was begun?

Yes _____ No _____ Don't remember _____

26a. (IF YES) What were they?

behavior modification _____

special diet _____

changes in classroom situation _____

psychiatric treatment _____

counselling _____

other (specify) _____

27. What medications, and dosages of medications have been used to treat (child's name) hyperactivity?

Medications

Dosage

Dates: From-To

Regimen

*28. Did you talk to (child's name) about what his/her medication is supposed to do for him/her?

Yes _____ No _____ Don't remember _____

*29. Did you talk to (child's name) parents about what the medication you prescribed for (child's name) is supposed to do?

Yes _____ No _____ Don't remember _____

*30. Did you adjust the dosage or regimen because of information from the parents or teacher?

Yes _____ No _____ Don't remember _____

30a. (IF YES) Who provided you with the information? _____

ADJUNCTIVE THERAPY

31. In addition to medication, have any other changes in (child's name) home life or school life been made or other treatments used to help (child's name)?

Yes _____ No _____ Don't know _____

31a. (IF YES) What approaches have been or are now being used? (NOTE: YOU NEED NOT READ THE LIST OF APPROACHES. CHECK THOSE MENTIONED BY RESPONDENT AND FOR THOSE MENTIONED, COLLECT THE ADDITIONAL INFORMATION.)

	(Check if Mentioned)	*Was it your idea to try this approach for (child's name)?	When did it Begin - End Dates From To	
Counselling	_____	_____	_____	_____
Megavitamin treatment	_____	_____	_____	_____
Special diet	_____	_____	_____	_____
Changes in your way of reacting to child	_____	_____	_____	_____
Psychiatric treatment	_____	_____	_____	_____
Special education	_____	_____	_____	_____
Changes in home life	_____	_____	_____	_____
Changes in class- room procedures	_____	_____	_____	_____
Counselling for parents	_____	_____	_____	_____
Behavior modi- fication	_____	_____	_____	_____
Other (specify)	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

ATTITUDINAL CONTEXT

32. Has (child's name) been treated unfairly by anyone because of his/her diagnosis or treatment?

Yes _____ No _____ Don't Know _____

- 32a. (IF YES) Who?

parents _____
 teachers _____
 other physician _____

school personnel _____
 other children _____
 relatives _____
 other (specify) _____

33. Do you think (child's name) might have a better chance for success in school if his/her teachers and other school personnel did not know about his/her diagnosis and treatment?

Yes _____ No _____ Don't Know _____
 School personnel not informed _____

34. Has the fact that (child's name) has been diagnosed as a "hyperactive child" seemed to make some people around him/her blind to (child's name) other qualities?

Yes _____ No _____ Don't Know _____

- 34a. (IF YES) Who tends to be this way? _____

35. Do you think (child's name) might be happier at school if others did not know of his/her diagnosis and treatment?

Yes _____ No _____ Don't Know _____

36. Do you think (child's name) might be happier at home if others did not know of his/her diagnosis and treatment?

Yes _____ No _____ Don't Know _____

37. Do you think (child's name) benefits at school because school personnel know of his/her diagnosis and treatment?

Yes _____ No _____ Don't Know _____

38. Do you think (child's name) benefits at home because the family knows of his/her diagnosis and treatment?

Yes _____ No _____ Don't Know _____

PSYCHOLOGICAL AND SOCIAL SUPPORT

- *39. Have you attempted to provide (child's name) parents with support and reassurance about their child?

Yes _____ No _____ Don't remember _____

40. Has the teacher expressed any frustrations or feelings of difficulty about teaching (child's name) to you?

Yes _____ No _____ Don't remember _____

- *40a. (IF YES) Have you tried to help her deal with these feelings?

Yes _____ No _____ Don't remember _____

41. Has (child's name) been teased or made fun of because he/she is taking medication?

Yes _____ No _____ Don't remember _____

- *42. Have you found that (child's name) is being teased at home?

Yes _____ No _____ Don't remember _____

- *42a. (IF YES) Did you do anything about it?

Yes _____ No _____ Don't know _____

- 42b. (IF YES) What have you done? _____

- *43. Have you found that (child's name) is being teased at school?

Yes _____ No _____ Don't know _____

- *43a. (IF YES) Did you do anything about it?

Yes _____ No _____ Don't know _____

- 43b. (IF YES) What have you done? _____

44. Do adults give (child's name) a "hard time" because he/she is taking medication?

Yes _____ No _____ Don't know _____

45. Does (child's name) have personal doubts or bad feelings that stem from the use of medication?

Yes _____ No _____ Don't know _____

46. Is treating the hyperkinetic child with stimulant medication more of an anxiety-provoking professional activity in comparison with treating other chronic childhood conditions (i.e. asthma, diabetes, etc.)?

very anxiety provoking _____
 somewhat _____
 very little _____
 less anxiety provoking _____
 not at all _____

- 46a. (IF VERY OR SOMEWHAT) To whom do you turn for support?

colleagues in same practice _____
 other physicians _____
 family members _____
 others (specify) _____
 no one _____

47. Do you ever provide psychological support for colleagues treating hyperkinetic children with stimulant medication?

Yes _____ No _____

*These items parallel to role items on pages A-67 thru A-102.

The first thing I'd like to do is to get some background information about (child's name) treatment for hyperactivity. I am going to ask you some questions. Your answers to these questions will give us a picture of (child's name) treatment.

(MONITORING)

1. How often do you see (child's name) for a check-up for his/her medication?

2. Who conducts the check-up?

(child's name) doctor _____

one of the other doctors in the combined practice _____

other (specify) _____

- *3. Do you conduct periodic examinations of (child's name) to monitor treatment?

Yes _____ No _____ Don't remember _____

- 3a. (IF YES) How are the periodic examinations scheduled?

Physician (I) set schedule _____

Physician (I) contacts parent when it is time for an examination _____

Child is seen when prescription is refilled _____

Parent brings child in when he/she thinks it necessary _____

Other (specify) _____

- *4. Do you get information directly from the teacher or other school personnel in order to evaluate (child's name) treatment?

Yes _____ No _____ Don't remember _____

- 4a. (IF YES) Is this information requested by you or volunteered by the teacher?

requested _____ volunteered _____ some volunteered, some requested _____

- 4b. (IF YES) What type of information do you get?

verbal description of child's school work _____

samples of school work _____

test results _____

written responses to a specific question sent to the teacher _____

other (specify) _____

5. What kinds of tests and procedures do you employ for (child's name) check-ups?

*6. Do you use information from the teacher in maintaining a dosage level for (child's name)?

Yes _____ No _____ Don't remember _____

*7. Do you use information about (child's name) behavior at home to help you evaluate the medication treatment?

Yes _____ No _____ Don't remember _____

* 8. Do you use information about (child's name) behavior in school to help you evaluate the medication treatment?

Yes _____ No _____ Don't remember _____

* 9. Do you use information about (child's name) behavior in the home to help you maintain a dosage level?

Yes _____ No _____ Don't remember _____

*10. Do you use information about (child's name) behavior at home to help you determine if the medication treatment has side effects?

Yes _____ No _____ Don't remember _____

*11. Do you use information about (child's name) behavior in school to help you determine if the medication treatment has side effects?

Yes _____ No _____ Don't remember _____

*12. Do you provide the teacher with information about (child's name) condition and treatment to help the teacher in working with (child's name) in the classroom?

Yes _____ No _____ Don't remember _____

*13. Have you obtained information from other sources about change in (child's name) behavior after medication began (such as school officials, scout leaders, relatives, etc.)?

Yes _____ No _____

*14. Have you consulted with new teachers at the beginning of the school year to help them relate to and teach (child's name)?

Yes _____ No _____ Don't remember _____

*15. Have you discontinued the administration of medication on a trial basis to see if (child's name) still needs it?

Yes _____ No _____ Don't remember _____

What I'd like to do now is get some background information about how (child's name) ended his/her medication treatment for hyperactivity. I am going to ask you some questions. Your answers to these questions will give us a picture of what happened when (child's name) ended treatment.

(TERMINATION)

1. Why was (child's name) medication stopped?

child no longer needed medication _____
medication doing no good _____
side effects were too great _____
child didn't like the idea of medication _____
parent didn't like the idea of medication _____
doctor didn't like the idea of medication _____
teacher didn't like the idea of medication _____
other (specify) _____

*2. Did you suggest that the medication be ended?

Yes _____ No _____ Don't remember _____

2a. (IF YES) To Whom? parent _____ teacher _____ child _____
other (specify) _____

3. When did (child's name) stop taking the medication? month _____
year _____

*4. Did you have an advanced indication of when (child's name) treatment would end?

Yes _____ No _____ Don't remember _____

4a. (IF YES) How far in advance did you know? _____

5. Did you make any special plans for the procedures for terminating (child's name) medication?

Yes _____ No _____ Don't remember _____

5a. (IF YES) What were they? _____

6. Did you try a trial discontinuation of medication as a method of finding if (child's name) medication should be stopped?

Yes _____ No _____ Don't remember _____

*7. Did you collect information from the teacher in order to decide whether to stop the medication?

Yes _____ No _____ Don't remember _____

7a. (IF YES) What sort of information did you gather?

verbal reports _____
 test results _____
 answers to specific questions asked _____
 written reports _____
 other (specify) _____

*8. Did you discuss ending medication treatment for (child's name) with his/her teacher?

Yes _____ No _____ Don't remember _____

*9. Did you conduct a physical examination of (child's name) to determine if the condition was sufficiently improved to discontinue medication?

Yes _____ No _____ Don't remember _____

9a. (IF YES) What tests and procedures did you use in conducting the examination?

*10. Did you discuss with (child's name) the possibility that medication might no longer be needed?

Yes _____ No _____ Don't remember _____

11a. (IF YES) Did you collect information from the teacher in order to decide whether to resume the medication?

Yes _____ No _____ Don't know _____

12. Did (child's name) have any fears or doubts about stopping the medication?

Yes _____ No _____ Don't know _____

12a. (IF YES) Do you know if anyone provided support for (child's name) when he/she ended medication?

Yes _____ No _____ Don't know _____

12b. (IF YES) Who? _____

*13. Did you counsel (child's name) parents about ways of dealing with child after stopping medication?

Yes _____ No _____ Don't remember _____

*14. Did you give directions to (child's name) parents about the disposal of medication when the treatment was ended?

Yes _____ No _____ Don't remember _____

*15. Did you conduct a post-medication examination for monitoring long range side effects of the medication treatment?

Yes _____ No _____ Don't know _____

15a. (IF YES) What procedures did you use for the examination? _____

*16. Did you discontinue medication at a time during the year that involved a minimum of stress for (child's name)?

Yes _____ No _____ Don't know _____

17. Was (child's name) placed on any other stimulant medication after he/she stopped taking stimulant medication?

Yes _____ No _____ Don't remember _____

17a. (IF YES) What medication? _____

17b. (IF YES) When? month _____ year _____

17c. (IF YES) Why? _____

EVENTS, PROCESS AND ROLE BEHAVIOR: Teachers

What I would like to do now is get some background information about how (child's name) came to be diagnosed as hyperactive and treated with medication. I am going to ask you some questions. Your answers to these questions will give us a picture of (child's name) diagnosis and treatment.

(PROBLEM RECOGNITION AND RESPONSE)

1. Who first brought up the idea that (child's name) had a learning or behavior problem?

child's mother _____

child's father _____

relative _____

child's teacher _____

child's doctor _____

other (specify) _____

don't know _____

don't remember _____

- 1a. (IF OTHER THAN SELF) How did you hear about the child's problem?

2. What problems was (child's name) thought to be having at that time?

3. When was this? Month _____ Year _____

4. Did you suspect any problem before this time?

Yes _____ No _____ Don't remember _____

- *5. Did you make the decision that (child's name) needed help?

Yes _____ No _____ Don't remember _____

- *5a. (IF NO) Did you take part in the decision to seek help for (child's name)?

Yes _____ No _____ Don't remember _____

*6. Did you make the decision to contact the doctor for medical help?

Yes _____ No _____ Don't remember _____

7. Did you contact a doctor for help?

Yes _____ No _____ Don't remember _____

*8. Were you the first person to bring up the idea that (child's name) needed medical help?

Yes _____ No _____ Don't remember _____

*9. Did you contact (child's name) parents for help?

Yes _____ No _____ Don't remember _____

*10. Did you go to any other source inside or outside the school system for help for (child's name)?

Yes _____ No _____ Don't remember _____

10a. (IF YES) Specify _____

(DIAGNOSIS)

11. Were you informed of (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

11a. (IF YES) From whom?

doctor	_____	school social worker	_____
doctor's nurse	_____	school nurse	_____
teacher	_____	school psychologist	_____
other (specify)	_____		

11b. (IF YES) What was the diagnosis? (IF RESPONDENT DOES NOT UNDERSTAND THE QUESTION, ASK: WHAT WAS THE MEDICAL TERM[S] THAT WAS USED TO DESCRIBE THE CHILD'S CONDITION?)

11c. (IF YES) When did you get word of diagnosis? Month _____ Year _____

- *12. Did you conduct or have conducted any tests or other diagnostic or evaluative procedures in order to develop an understanding of the nature of (child's name) condition?

Yes _____ No _____ Don't remember _____

- 12a. (IF YES) What tests or procedures did you - or others in the school system - conduct?

- *13. Did you talk with the doctor about the child's behavior and learning in school?

Yes _____ No _____ Don't remember _____

- 13a. (IF YES) Who requested this discussion?

- *14. Did you record the medical diagnosis in (child's name) cumulative record?

Yes _____ No _____ Don't remember _____

- *15. Did you communicate (child's name) medical diagnosis to others in the school system?

Yes _____ No _____ Don't remember _____

- 15a. (IF YES) With whom did you communicate about (child's name) diagnosis?

principal	_____	physical education teacher	_____
school nurse	_____	reading teacher	_____
school social worker	_____	teacher aides	_____
school psychologist	_____	others (please specify)	_____

16. Do you feel that you were of help in arriving at (child's name) diagnosis?

Yes _____ No _____ Don't remember _____

- *17. Did you suggest that (child's name) might be hyperactive before the doctor made the diagnosis?

Yes _____ No _____ Don't remember _____

18. Did anyone else in the school system suggest that (child's name) might be hyperactive before the doctor made the diagnosis?

Yes _____ No _____ Don't remember _____

- 18a. (IF YES) Who?

- *19. Did you provide information (i.e. test results, observation, anecdotes about child's behavior, samples of work) as part of the diagnostic process?
Yes _____ No _____ Don't remember _____
- *20. Did you talk with the doctor about the details and meaning of (child's name) diagnosis?
Yes _____ No _____ Don't remember _____
- 20a. (IF YES) Do you feel your talk with the doctor enabled you to understand (child's name) condition?
Yes _____ No _____ Don't remember _____
- 20b. (IF YES) What, if anything, did you find out that was helpful and important for you to know? _____

- 20c. (IF YES) What questions or concerns, if any, did you have that were not answered by the doctor when you talked with the doctor about the meaning of (child's name) diagnosis? _____

- *21. Did you talk with the parents about the details and meaning of (child's name) diagnosis?
Yes _____ No _____ Don't remember _____
- 21a. (IF YES) Do you feel this helped you to understand the child's condition or his/her school situation?
Yes _____ No _____ Don't remember _____
- 21b. (IF YES) What did you find out that was helpful and important for you to know? _____

- 21c. (IF YES) What questions or concerns, if any, did you have that were not answered by the parents? _____

- *22. Did you discuss the details and meaning of (child's name) condition with (child's name)?
Yes _____ No _____ Don't remember _____
- *23. Did you discuss the nature of (child's name)-condition with the class?
Yes _____ No _____ Don't remember _____

(MEDICATION TREATMENT)

24. When was the decision to place the child on medication made?
 Month _____ Year _____
- *25. Did you recommend the use of medication?
 Yes _____ No _____ Don't remember _____
- 25a. (IF YES) Was it a specific medication? Yes _____ No _____
- 25b. (IF YES) What was it? _____
26. Whose decision was it to use medication treatment for (child's name)?
 (CHECK MORE THAN ONE RESPONSE IF THE DECISION IS SEEN AS A JOINT DECISION.)
- teacher _____
 doctor _____
 parent _____
 other (please specify) _____
 other school personnel (specify) _____
- *27. Did you tell the others in the school system that (child's name) was being treated with medication?
 Yes _____ No _____ Don't remember _____
- 27a. (IF YES) Who?
- school psychologist _____
 principal _____
 physical education teacher _____
 music or reading teacher _____
 school social worker _____
 reading teacher _____
 other (please specify) _____
28. Did you record in (child's name) cumulative record that he/she was being treated with medication?
 Yes _____ No _____ Don't remember _____
29. Were any other means of dealing with (child's name) tried before medication was begun?
 Yes _____ No _____ Don't remember _____
- 29a. (IF YES) What were they?
- behavior modification _____
 special diet _____
 changes in classroom situation _____
 psychiatric treatment _____
 counselling _____
 other (please specify) _____

30. Has there been any change in the medication treatment of (child's name) since treatment began?

Yes _____ No _____ Don't remember _____

30a. (IF YES) What change was there?

dosage _____

type of medication _____

time at which medication was given _____

other (please specify) _____

*31. Do you give (child's name) pill to him/her each time he/she takes it at school?

Yes _____ No _____

31a. (IF NO) Do you know who sees to it that (child's name) takes his/her medication at school?

Yes (specify) _____ No _____

32. Where is the medicine stored at school? _____

*33. Did you talk to (child's name) about what his/her medication is supposed to do for him/her?

Yes _____ No _____ Don't remember _____

*34. Did you adjust the dosage or the times when (child's name) takes his/her medication because of his/her performance in school?

Yes _____ No _____ Don't remember _____

(ADJUNCTIVE THERAPY)

35. In addition to medication, have any other changes in (child's name) home life or school life been made or other treatments used to help (child's name)?

Yes _____ No _____ Don't know _____

- 35a. (IF YES) What approaches have been or are now being used? (NOTE: YOU NEED NOT READ THE LIST OF APPROACHES. CHECK THOSE MENTIONED BY RESPONDENT AND FOR THOSE MENTIONED, COLLECT THE ADDITIONAL INFORMATION.)

	(Check if Mentioned)	Was it your idea to try this approach for (child's name)?	When did it Begin - End Dates From To	
Counselling	_____	_____	_____	_____
Megavitamin treatment	_____	_____	_____	_____
Special diet	_____	_____	_____	_____
Changes in your way of reacting to child	_____	_____	_____	_____
Psychiatric treatment	_____	_____	_____	_____
Special education	_____	_____	_____	_____
Changes in home life	_____	_____	_____	_____
Changes in class- room procedures	_____	_____	_____	_____
Counselling for parents	_____	_____	_____	_____
Behavior modi- fication	_____	_____	_____	_____
Other (specify)	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

(ATTITUDINAL CONTEXT)

36. Has (child's name) been treated unfairly by anyone because of his/her diagnosis or treatment?
 Yes _____ No _____ Don't Know _____
- 36a. (IF YES) Who?
 parents _____ school personnel _____
 teachers _____ other children _____
 doctors _____ relatives _____
 other (specify) _____
37. Do you think (child's name) might have a better chance for success in school if his/her teachers and other school personnel did not know about his/her diagnosis and treatment?
 Yes _____ No _____ Don't Know _____
 School Personnel not informed. _____
38. Has the fact that (child's name) has been diagnosed as a "hyperactive child" seemed to make some people around him/her blind to (child's name) other qualities?
 Yes _____ No _____ Don't Know _____
- 38a. (IF YES) Who tends to be this way? _____
39. Do you think (child's name) might be happier at school if others did not know of his/her diagnosis and treatment?
 Yes _____ No _____ Don't Know _____
 Others not informed _____
40. Do you think (child's name) benefits at school because school personnel know of his/her diagnosis and treatment?
 Yes _____ No _____ Don't Know _____
 Others not informed _____

(PSYCHOLOGICAL AND SOCIAL SUPPORT)

41. Have you attempted to provide (child's name) parents with support and reassurance about their child?
 Yes _____ No _____ Don't Remember _____

42. Has (child's name) been teased or made fun of at school because he/she is taking medication?

Yes _____ No _____ Don't remember _____

*42a. (IF YES) What was your response to this? _____

43. Do any adults give (child's name) a "hard time" because he/she is taking medication?

Yes _____ No _____ Don't Know _____

43a. (IF YES) What, if anything, did you do about this? _____

44. Does (child's name) have personal doubts or bad feelings that stem from the use of medication?

Yes _____ No _____ Don't Know _____

*44a. (IF YES) Have you helped (child's name) to deal with these doubts and feelings that stemmed from the use of medication?

Yes _____ No _____ Don't Know _____

*These items parallel to role items on pages A-67 thru A-102.

EVENTS, PROCESS AND ROLE BEHAVIOR: Teachers

The first thing I'd like to do is get some background information about (child's name) treatment for hyperactivity. I am going to ask you some questions. Your answers to these questions will give us a picture of (child's name) treatment.

(MONITORING)

- *1. Do you provide the physician with information to help him evaluate the treatment for (child's name)?
Yes _____ No _____ Don't remember _____
- *2. Do you provide the physician with information to help him determine if the medication has side effects for (child's name)?
Yes _____ No _____ Don't remember _____
- *3. Do you provide the physician with information which helps him maintain a dosage level for (child's name)?
Yes _____ No _____ Don't remember _____
- *4. Have you obtained information from other sources about change in (child's name) behavior after medication began (such as school officials, scout leaders, relatives, etc.)?
Yes _____ No _____ Don't remember _____
5. How often do you have a meeting with (child's name) parents to discuss how things are going with (child's name)?
- never _____
once a year _____
couple times a year _____
once a month _____
more than once a month _____
other (specify) _____
when I think it is necessary _____
when the parent requests it _____
6. In the past year how many meetings have you had with (child's name) parent(s) to discuss how things are going? _____
7. On the average how often do you meet with the parents of the children in your class during the year? _____
- *8. Have you stopped the administration of medication on a trial basis to see if (child's name) still needs it?
Yes _____ No _____ Don't remember _____
- *9. Have you suggested medication be stopped on a trial basis to see if (child's name) still needs it?
Yes _____ No _____ Don't remember _____

9a. (IF YES) To whom did you suggest this?

parents _____
 physician _____
 school specialist _____
 child _____
 other (specify) _____

10. Do you provide periodic reports to the doctor about changes in (child's name) behavior in class?

Yes _____ No _____ Don't remember _____

10a. (IF YES) Is this requested or volunteered?

requested _____ Some requested, some volunteered _____
 volunteered _____

10b. (IF YES) What type of information have you provided the doctor?

verbal descriptions of child's work _____
 samples of school work _____
 test results _____
 written responses to specific questions sent by physician _____
 other (specify) _____

11. Have you requested that medication for (child's name) be discontinued?

Yes _____ No _____ Don't remember _____

(PSYCHOLOGICAL AND SOCIAL SUPPORT)

- *18. Have you attempted to provide (child's name) parents with support and reassurance about their child?

Yes _____ No _____ Don't remember _____

19. Has (child's name) been teased or made fun of because he/she is taking medication?

Yes _____ No _____ Don't know _____

- *20. Have you found that (child's name) is being teased at home?

Yes _____ No _____ Don't know _____

- *20a. (IF YES) Did you do anything about it?

Yes _____ No _____ Don't remember _____

- 20b. (IF YES) What have you done? _____

- *21. Have you found that (child's name) is being teased at school?

Yes _____ No _____ Don't know _____

- *21a. (IF YES) Did you do anything about it?

Yes _____ No _____ Don't remember _____

- 21b. (IF YES) What have you done? _____

22. Do any adults give (child's name) a hard time because he/she is taking medication?

Yes _____ No _____ Don't know _____

- 22a. (IF YES) What, if anything, did you do about this? _____

23. Does (child's name) seem to have personal doubts or bad feelings that seem to stem from the use of medication?

Yes _____ No _____ Don't know _____

- 23a. (IF YES) Have you helped (child's name) to deal with these doubts and feelings that stemmed from the use of medication?

Yes _____ No _____ Don't know _____

EVENTS, PROCESS AND ROLE BEHAVIOR: Teachers

The first thing I'd like to do is to get some background information about how (child's name) ended his/her medication treatment for hyperactivity. I am going to ask you some questions. Your answers to these questions will give us a picture of what happened when (child's name) ended treatment.

(TERMINATION)

1. Why was (child's name) medication stopped?

child no longer needed medication _____

medication doing no good _____

side effects were too great _____

child didn't like the idea of medication _____

parent didn't like the idea of medication _____

doctor didn't like the idea of medication _____

teacher didn't like the idea of medication _____

don't know _____

other (specify) _____

*2. Did you suggest that the medication be ended?

Yes _____ No _____ Don't Know _____

2a. (IF YES) To whom?

parent _____ other school personnel _____ child _____

doctor _____ other (specify) _____

3. When did (child's name) stop taking the medication?

Month _____ , Year _____ Don't know _____

*4. Did you discuss with (child's name) the possibility that medication might no longer be needed?

Yes _____ No _____ Don't remember _____

5. Was medication for (child's name) started again at any time after being stopped?

Yes _____ No _____ Don't remember _____

*5a. (IF YES) Did you recommend to (child's name) parents that medication be resumed?

Yes _____ No _____ Don't remember _____

*5b. (IF YES) Did you recommend (child's name) doctor that medication be resumed?

Yes _____ No _____ Don't remember _____

*5c. (IF YES) Did (child's name) request that medication be resumed?

Yes _____ No _____ Don't remember _____

6. Did (child's name) have any fears or doubts about stopping the medication?
 Yes _____ No _____ Don't know _____

*6a. (IF YES) Do you know if anyone provided reassurance for (child's name) when he/she ended medication?

Yes _____ No _____ Don't know _____

6b. (IF YES) Who ? _____

*7. Did you make any changes in (child's name) educational program or in your classrooms interaction with him/her after (child's name) ended medication?

Yes _____ No _____ Don't remember _____

*8. Did you advise (child's name) parents about ways of dealing with child after stopping medication?

Yes _____ No _____ Don't remember _____

(ATTITUDINAL CONTEXT)

9. Has (child's name) been treated unfairly by anyone because of his/her diagnosis or treatment?

Yes _____ No _____ Don't know _____

9a. (IF YES) Who?

parents _____

teachers _____

physician _____

other (specify) _____

school personnel _____

other children _____

relatives _____

10. Do you think (child's name) might have had a better chance for success in school if teachers and other school personnel did not know about his/her diagnosis and treatment?

Yes _____ No _____ Don't know _____

School Personnel did not know _____

11. Did the fact that (child's name) was diagnosed as hyperactive make some people around him/her blind to (child's name) other qualities?

Yes _____ No _____ Don't know _____

11a. (IF YES) Who tended to be this way? _____

12. Do you think (child's name) might have been happier at school if others had not known of his/her diagnosis and treatment?

Yes _____ No _____ Don't know _____

13. Do you think (child's name) benefited at school because school personnel knew of his/her diagnosis and treatment?
 Yes _____ No _____ Don't know _____

(PSYCHOLOGICAL AND SOCIAL SUPPORT)

- *14. Did you attempt to provide (child's name) parents with support and reassurance about their child?
 Yes _____ No _____ Don't remember _____

15. Was (child's name) teased or made fun of because he/she was taking medication?
 Yes _____ No _____ Don't know _____

- *16. Did you find that (child's name) was being teased at home?
 Yes _____ No _____ Don't remember _____

- *16a. (IF YES) Did you do anything about it?
 Yes _____ No _____ Don't know _____

- 16b. (IF YES) What did you do? _____

- *17. Did you find that (child's name) was being teased at school?
 Yes _____ No _____ Don't know _____

- *17a. (IF YES) Did you do anything about it?
 Yes _____ No _____ Don't know _____

- 17b. (IF YES) What did you do? _____

18. Did any adults give (child's name) a "hard time" because he/she was taking medication?
 Yes _____ No _____ Don't know _____

19. (IF YES) What if anything did you do about this? _____

20. Did (child's name) have personal doubts or bad feelings that seemed to stem from the use of medication?
 Yes _____ No _____ Don't know _____

- 20a. (IF YES) Have you helped (child's name) to deal with these doubts and feelings that stemmed from the use of medication?
 Yes _____ No _____ Don't know _____

*These items parallel to role items on pages A-78 thru A-102.

How do you feel about the fact that (child's name) received medication treatment?

(READ QUESTION, THEN HAND RESPONDENT ANSWER SHEET AND RECORD ANSWER ON THIS PAGE.)

- _____ I strongly believe that the treatment of (child's name) with medication was a good thing.
- _____ I have some misgivings about the use of medication but think it was a good thing for (child's name).
- _____ While I see something in its favor, I don't think it was a good thing for (child's name).
- _____ I strongly believe that the treatment of (child's name) with medication was a bad thing.
- _____ I have no opinion about (child's name) treatment with medication.

EVENTS AND PROCESS: Child (Treated)

AIM: This section is to find out if the child has participated actively in the process of being treated with stimulant medication. By active participation is meant whether the child influenced the process by which he was diagnosed or prescribed, or altered the course of the treatment.

1. How did you start taking medicine? Whose idea was it?

☐ Mother, father, or parents

☐ Teacher or other school personnel

☐ Physician

☐ Self

☐ Other members of the family _____

☐ Don't know

☐ Other

Critical incident (DESCRIBE) _____

2. INITIAL QUESTION: Did you ask your teacher or your parents or your doctor any questions about being given your pills or medicine?

☐ Yes

☐ No

PROBE: (Use this only if child CANNOT respond to question.) Before you began taking your pills or medication did you talk to anyone about taking them?

☐ Yes

☐ No

- 2a. (IF YES) Who did you talk to?

☐ doctor

☐ teacher

☐ parent

☐ other

- 2b. (IF YES) What did you talk about? _____

3. Did you ever talk to your teacher or parents or doctor about changing anything about your medicine or pills — what you are taking, when you take it or how many you take?

☐ Yes
☐ No

- 3a. (IF YES): Who did you talk to?

☐ doctor
☐ teacher
☐ parents
☐ other

- 3b. What did you say? (NOTE: BE SURE TO CLARIFY WHAT WAS SAID TO WHOM.)

4. Did you ever talk to your teacher or parents or doctor about stopping the medicine or pills?

☐ Yes
☐ No

- 4a. (IF YES): Who did you talk to?

☐ doctor
☐ teacher
☐ parents
☐ other

- 4b. What did you say?

ASSESSMENT

I would now like to ask you a couple of questions about (child's name) condition and your view of his/her treatment. We would like to get your own feelings about this which might be different from how the teacher or doctor feels.

1. How serious was (child's name) problem before medication treatment began? Please take this (HAND THEM THEIR SEPARATE COPY OF THE CONTINUUM FOR "RATING OF PROBLEM") and put a check anywhere on the line where it will best show how you rate (child's name) problem.

Normal No Problem	Borderline Problem	Mild Problem	Moderate Problem	Consider- able Problem	Severe Problem	Almost Intolerable to Live With
----------------------	-----------------------	-----------------	---------------------	------------------------------	-------------------	---------------------------------------

2. How much has (child's name) condition changed since medication treatment began? Please take this (HAND THEM THEIR SEPARATE COPY OF THE CONTINUUM FOR "CHANGE IN CONDITION") and put a check anywhere on the line where it best shows how you rate (child's name) change in condition from the beginning of treatment to the present time.

Very Much Improved	Much Improved	Slightly Improved	Condition the Same: Not Better- Not Worse	Slightly Worse	Much Worse	Very Much Worse
-----------------------	------------------	----------------------	--	-------------------	---------------	--------------------

Sometimes people have unpleasant reactions to medicine, sometimes called side effects. For example, antihistamines may make some people sleepy. Do you understand what I mean by side effects? (IF NO, EXEMPLIFY AGAIN, E.G. ASPIRIN, WHILE TAKING CARE OF YOUR HEADACHE, MAY HAVE THE SIDE EFFECT OF UPSETTING YOUR STOMACH.)

3. Has (child's name) had any side effects from his/her medication?

Yes _____ No _____

3a. (IF YES) What were they? _____

3b. (IF YES) Please take this (HAND THEM THEIR SEPARATE CONTINUUM FOR "SIDE EFFECTS") and put a check anywhere on the line where it best shows how troublesome side effects in general were when they occurred.

Barely Noticeable	Quite Mild	Pronounced	Severe	Severe Requiring Discontinuation of Medication
----------------------	---------------	------------	--------	---

I would now like to ask you a couple of questions about (child's name) condition and your view of his/her treatment. We would like to get your own feelings about this which might be different from how the teacher or doctor feels.

Estimate of Problem Before Treatment

1. Can you estimate for me how serious (child's name) problem was before treatment began? Yes _____ No _____ (ACCEPT A NOD OR GESTURE AS YES)

IF YES: Please take this (HAND THEM THE CONTINUUM FOR "ESTIMATE OF PROBLEM") and put a check which shows how you rate (child's name) problem.

Normal No Problem	Borderline Problem	Mild Problem	Moderate Problem	Consider- able Problem	Severe Problem	Among the Most Serious Problems I Have Seen in My Patients
----------------------	-----------------------	-----------------	---------------------	------------------------------	-------------------	--

2. How much has (child's name) condition changed since medication treatment began? Please take this (HAND THEM THEIR SEPARATE COPY OF THE CONTINUUM FOR "CHANGE IN CONDITION") and put a check anywhere on the line where it best shows how you rate (child's name) change in condition from the beginning of treatment to the present time.

Very Much Improved	Much Improved	Slightly Improved	Condition the Same: Not Better- Not Worse	Slightly Worse	Much Worse	Very Much Worse
-----------------------	------------------	----------------------	--	-------------------	---------------	--------------------

3. Has (child's name) had any side effects from his/her medication?

Yes _____ No _____

3a. (IF YES) What were they? _____

3b. (IF YES) Please take this (HAND THEM THEIR SEPARATE CONTINUUM FOR "SIDE EFFECTS") and put a check anywhere on the line where it best shows how troublesome side effects in general were when they occurred.

Barely Noticeable	Quite Mild	Pronounced	Severe	Severe Requiring Discontinu- ation of Medication
----------------------	---------------	------------	--------	--

I would now like to ask you a couple of questions about (child's name) condition and your view of his/her treatment. We would like to get your own feelings about this which might be different from how the parent or doctor feels.

1. How serious was (child's name) problem before medication treatment began? Please take this (HAND THEM THEIR SEPARATE COPY OF THE CONTINUUM FOR "RATING OF PROBLEM") and put a check anywhere on the line where it will best show how you rate (child's name) problem.

Normal No Problem	Borderline Problem	Mild Problem	Moderate Problem	Consider- able Problem	Severe Problem	Among the Most Serious Problems I Have Seen in My Students
----------------------	-----------------------	-----------------	---------------------	------------------------------	-------------------	--

2. How much has (child's name) condition changed since medication treatment began? Please take this (HAND THEM THEIR SEPARATE COPY OF THE CONTINUUM FOR "CHANGE IN CONDITION") and put a check anywhere on the line where it best shows how you rate (child's name) change in condition from the beginning of treatment to the present time.

Very Much Improved	Much Improved	Slightly Improved	Condition the Same: Not Better- Not Worse	Slightly Worse	Much Worse	Very Much Worse
-----------------------	------------------	----------------------	--	-------------------	---------------	--------------------

Sometimes people have unpleasant reactions to medicine, sometimes called side effects. For example, antihistamines may make some people sleepy. Do you understand what I mean by side effects? (IF NO, EXEMPLIFY AGAIN, E.G. ASPIRIN, WHILE TAKING CARE OF YOUR HEADACHE, MAY HAVE THE SIDE EFFECT OF UPSETTING YOUR STOMACH.)

3. Has (child's name) had any side effects from his/her medication?

Yes _____ No _____

3a. (IF YES) What were they? _____

3b. (IF YES) Please take this (HAND THEM THEIR SEPARATE CONTINUUM FOR "SIDE EFFECTS") and put a check anywhere on the line where it best shows how troublesome side effects in general were when they occurred.

Barely Noticeable	Quite Mild	Pronounced	Severe	Severe Requiring Discontinuation of Medication
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ASSESSMENT: Child (Treated)

1. Sometimes medicines help and sometimes they do not. Has your medicine helped you?
 - ☐ Don't know
 - ☐ Yes, very much
 - ☐ Yes, some
 - ☐ No
2. When a person is taking medicine or pills is work harder or easier in school?
 - ☐ Harder
 - ☐ Easier
 - ☐ About the same
 - ☐ Don't know
3. When a person is taking medicine or pills is it easier or harder to be with friends?
 - ☐ Easier
 - ☐ About the same
 - ☐ Harder
 - ☐ Don't know
4. What happens when you forget to take your medicine?
 - ☐ I never forget
 - ☐ Can't tell
 - ☐ Get angry, mad, mean
 - ☐ Feel nervous
 - ☐ Activity problems - restless
 - ☐ Problems at home
 - ☐ Problems with friends
 - ☐ Problems with school work
 - ☐ Get sick
 - ☐ Other: _____
 - ☐ Don't know
- 4a. (IF YES): Can other people tell when you forgot to take the medicine? Who?
 - ☐ No
 - ☐ Yes - sibs
 - ☐ Yes - parents
 - ☐ Yes - teacher
 - ☐ Yes - peers
 - ☐ Yes - other _____
 - ☐ Don't know
5. Do you think you would be better off if you could stop taking the medicine now? (ASK FOR INITIATION AND MONITORING)
 - ☐ Yes
 - ☐ No
 - ☐ Don't know

6. Is there anything about taking the medicine that you don't like?

☐ No
☐ Yes

6a. (IF YES) What is it?

ROLE

We now come to a more general part of the interview. Before we were talking about (child's name), but now we will be talking in general about children who are being treated for hyperactivity. The next questions will deal with your view of what parents, teachers, and doctors should or should not do for hyperactive children and whose job it should be to do it. I would like to find out what you think should happen, rather than what actually happened.

1. Do you believe that parents, doctors, teachers, and others should be responsible for finding out if a child might have behavior or learning problems?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Whose job do you think it should be to find out if a child has a behavior or learning problem? (CHECK AS MANY AS THEY MENTION.)

- 1) M.D. _____
2) Parent _____
3) Teacher _____
4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person mentioned has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this? *

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

* (NOTE: IF, IN THIS SET OF QUESTIONS, RESPONDENT IS UNCLEAR ABOUT WHAT "THIS" MEANS, USE THE LANGUAGE IN PART A STEM. FOR EXAMPLE, 1) WOULD READ, "SHOULD THE TEACHER FIND OUT IF A CHILD HAS A BEHAVIOR OR LEARNING PROBLEM?" DO THIS WHEN NECESSARY FOR ALL 35 ROLE ITEMS.)

2. Do you believe that medical help should be sought for a child who seems to be hyperactive?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should seek the medical help?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person mentioned has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

3. In addition to the child's own doctor, should another doctor--a specialist--be consulted?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should request the consultation?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person mentioned has equal responsibility. _____

The person with major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IS WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

4. Should information about the child's school performance be a part of diagnosing hyperactivity?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that this information is at hand when the diagnosis is made?

- 1) M.D. _____
 2) Teacher _____
 3) Parent _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person mentioned has equal responsibility. _____

The person with major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IS WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

5. Should the parents understand the details and meaning of the medical diagnosis of their child?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should be responsible for the parents' understanding of the diagnosis?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this? *

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

6. Should the teacher understand the details and meaning of the medical diagnosis of her student?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should be responsible for the teacher's understanding of the diagnosis?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

7. Should the child understand the details and meaning of the medical diagnosis of his/her condition?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should be responsible for the child's understanding of his/her diagnosis?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

8. Should tests or other diagnostic procedures be conducted in order to evaluate the child's condition?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Whose job should it be to conduct the tests and other diagnostic procedures?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS ALREADY MENTIONED.

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

9. Should the diagnosis of hyperactivity for a child be told to school personnel who will come in contact with the child?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Whose job should it be to tell school personnel?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

10. Should the diagnosis of hyperactivity and the use of medication be put into official school records? A-77

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that the diagnosis of hyperactivity and use of medication for a child is put in school records?

- 1) M.D. _____
2) Parent _____
3) Teacher _____
4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

11. Should the diagnosis of a child as hyperactive be told to other school children in the class?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should tell the other school children?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

(READ TO SUBJECT) I would just like you to know that we are about half way through.

12. Should information about a child's behavior at home be a part of diagnosing hyperactivity?

Usually should _____

Usually should not _____

- A. (IF SHOULD) Who should see to it that information is at hand when the diagnosis is made?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

13. Should ~~someone~~ other than the doctor suggest to the doctor a possible diagnosis of hyperactivity for a child?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should suggest this?

- 1) Parent _____
 2) Teacher _____
 3) Other _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING TWO PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

14. Should the use of medication be recommended for a child who is diagnosed as hyperactive?

Usually should _____

Usually should not _____

- A. (IF SHOULD) Who should make this recommendation?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

15. When the hyperactive child is being treated with medication, should the use of medication be explained to other members of the household old enough to understand?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should make this explanation?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

16. Should the teacher of a hyperactive child being treated with medication have an explanation of that medication?

Usually should _____

Usually should not _____

- A. (IF SHOULD) Who should be responsible for the teacher's understanding of the medication?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

17. Should students in the class of a hyperactive child being treated with medication have an explanation of the medication treatment?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should explain it to them?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

18. Should a hyperactive child being treated with medication have an explanation of that medication treatment?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should explain it to him/her?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ . Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

19. Should a hyperactive child taking medication be given each dose by an adult?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should give the child each dose?

- 1) Parent _____
 2) Teacher _____
 3) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

20. Should reports about the child from home be used to adjust the medication and the times when the medication is taken?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that this information is at hand when these adjustments are made?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

21. Should information about the child from the school be used to adjust the medication and the times when the medication is taken?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that this information is at hand when these adjustments are made?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

22. In addition to medication, should any other changes be made in the life of the hyperactive child, such as other treatments and approaches or changes in the home and school situation?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should decide what changes are needed?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

23. Should a program of regular visits to the doctor be set-up for the hyperactive child being treated with medication?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should set this up?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

24. Should information from the home be used to judge the effectiveness of the medication treatment?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that this information is at hand when the effectiveness of the treatment is judged?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

25. Should information from the school be used to judge the effectiveness of the medication treatment?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that this information is at hand when the effectiveness of the treatment is judged?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

26. Should information from the home be used to find out if the medication has resulted in harmful side effects?

Usually should _____

Usually should not _____

- A. (IF SHOULD) Who should see to it that the information about side effects is at hand when treatment is evaluated?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

27. Should information from the school be used to find out if the medication has resulted in harmful side effects?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that this information about side effects is at hand when treatment is evaluated?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

28. Should there be a channel for information between the teacher and the physician of a hyperactive child being treated with medication?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should set-up this channel?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

29. Should parents of hyperactive children be provided with support and reassurance about their child and the treatment being given their child?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should provide that support and reassurance?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

30. Should the medication treatment be ended as soon as it is believed that it might not be needed?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should decide to end the medication?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

31. Should a trial ending of medication be used as a method of finding out if medication treatment should be ended?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should decide if there should be a trial ending of medication?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

32. Should information from the school be used in order to decide whether or not medication treatment should be ended?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should see to it that this information is at hand when the decision about ending medication is being made?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

33.. Should a physical examination be required to determine if medication treatment can be ended?

Usually should _____

Usually should not _____

A. (IF SHOULD) Who should see to it that this examination occurs?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

34. Should medication treatment be begun again if there is some chance that it might help the child?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should decide to begin the medication treatment?

- 1) M.D. _____
- 2) Parent _____
- 3) Teacher _____
- 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
Should _____ Should not _____ OK but not required _____

35. Should routine follow-up examination and other special assistance be provided after medication treatment has ended?

Usually should _____ Usually should not _____

- A. (IF SHOULD) Who should be responsible for seeing to it that this happens?

- 1) M.D. _____
 2) Parent _____
 3) Teacher _____
 4) Other (specify) _____

- B. (IF YOU CHECKED MORE THAN ONE IN "A" ABOVE:) Are they (PEOPLE CHECKED ABOVE) equally responsible or does one have the main responsibility?

Each person has equal responsibility. _____

The person with the major responsibility is _____.

- C. (IF ANY OF THE FOLLOWING THREE PERSONS HAS BEEN MENTIONED, JUST CHECK THAT IT WAS "ALREADY MENTIONED.")

- 1) Should the teacher also do this?

Teacher already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 2) Should the doctor also do this?

Doctor already mentioned above _____
 Should _____ Should not _____ OK but not required _____

- 3) Should the parent also do this?

Parent already mentioned above _____
 Should _____ Should not _____ OK but not required _____

(READ TO RESPONDENT:) I appreciate your patience and all the information you're giving me. We are almost finished.

ATTITUDE (GENERAL)

Now I would like to find out about your feelings toward medication for hyperactive children. Much has been written and said about the use of medication for treating hyperactive children. Please tell me if you agree or disagree with the following points of view.

- | | |
|--------------------------|---|
| AGREE ____ DISAGREE ____ | 1. While the use of medication may be necessary for a small percentage of children, their use has become too widespread. |
| AGREE ____ DISAGREE ____ | 2. Most doctors are careful in prescribing this medication and they work well for hyperactive children. |
| AGREE ____ DISAGREE ____ | 3. There is so much confusion about what hyperactivity is, that the use of medication is questionable. |
| AGREE ____ DISAGREE ____ | 4. Not enough is known about the dangers of medication to make it a safe approach. |
| AGREE ____ DISAGREE ____ | 5. It is never proper to use medication to tamper with the minds of children in school. |
| AGREE ____ DISAGREE ____ | 6. For children who need them, these medicines are almost a miracle. |
| AGREE ____ DISAGREE ____ | 7. It's a shame to let children suffer when there are medicines like these that can help them. |
| AGREE ____ DISAGREE ____ | 8. Medication is not the total solution for the hyperactive child, but it is a useful and important part of the solution. |

ATTITUDE: Child (Treated)

1. Which of these sounds like what you would say about taking the medicine?
- ☐ It is a good thing.
 - ☐ There are some good things and some bad things about it.
 - ☐ It is a bad thing.
 - ☐ I don't know if it is a good thing or a bad thing.

SPECIFIC BELIEFS

This set of questions is about your beliefs and opinions about hyperactivity and its treatment. There are many different views about this. We want to understand your own feelings and opinions.

1. If you were asked to explain what hyperactivity is, could you explain it?

Yes _____ No _____

- 1a. (IF YES) How would you explain what hyperactivity is?

2. Do you have any opinions about what causes hyperactivity in children?

Yes _____ No _____

- 2a. (IF YES) What do you believe causes hyperactivity?

Please answer each of the following statements "agree" if you agree, "disagree" if you do not agree, and "don't know" if you don't know. I would like to remind you that there are many different opinions about these issues. Don't worry about trying to give what others think is the right answer.

AGREE _____ DISAGREE _____ DON'T KNOW _____

3. At least some cases of hyperactivity are caused by a physiological, neurological, or other medical disorder.

AGREE _____ DISAGREE _____ DON'T KNOW _____

4. At least some cases of hyperactivity are caused by psychological or emotional problems.

- AGREE ___ DISAGREE ___ DON'T KNOW ___ 5. At least some cases of hyperactivity are caused by poor nutrition.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 6. At least some cases of hyperactivity are caused by poor social conditions.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 7. At least some cases of hyperactivity are caused by food additives.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 8. At least some cases of hyperactivity are caused by poor schools or teachers.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 9. At least some cases of hyperactivity are caused by lead poisoning.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 10. The term "hyperactive" is used to characterize children who are energetic, active, creative, or merely restless.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 11. In some instances, it may be a good thing for a child to be hyperactive.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 12. The term "hyperactive" is used by people to make it possible for them to control or suppress children.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 13. The term "hyperactive" is a legitimate diagnosis of a real problem for some children.

14. What is the typical length of time that children stay on medication for hyperactivity?

Don't know

There is no typical regimen, i.e., too variable to say

A few weeks

A few months

One to 14 years

Until puberty—adolescence

15. Do you know if medication which is used to treat hyperactive children can produce side effects? What side effects can (not necessarily will) medication produce? (CHECK THOSE MENTIONED BY RESPONDENT. DO NOT READ LIST.)

headaches

loss of appetite

stomachaches

insomnia

weight and height deficit

irritability

restlessness

depression

other (specify)

don't know

16. Have you heard or read criticism of medication for hyperactive children?

Yes _____ No _____

16a. (IF YES) Do you happen to remember the criticism?

Yes _____ No _____

16b. (IF YES) Please mention some of the criticisms:

(Child's name) is taking _____ (SPECIFY MEDICATION AND
WRITE IT IN THE BLANK.)

Would you answer the following questions about this medication yes, no, or
don't know?

17. This medication is a tranquilizer.

Yes _____ No _____ Don't know _____

18. This medication is habit forming.

Yes _____ No _____ Don't know _____

19. This medication increases the child's intelligence.

Yes _____ No _____ Don't know _____

20. This medication is a stimulant.

Yes _____ No _____ Don't know _____

21. This medication may lead to illegal drug use later in life.

Yes _____ No _____ Don't know _____

SPECIFIC BELIEFS: Physicians

This set of questions is about your professional beliefs and assessments about hyperactivity and its treatment. There are many different views about this. We want to understand your medical perspectives.

(HAND PHYSICIAN "TERM SHEET")

1. Do any of these terms seem to you inappropriate, useless, or invalid in describing the condition diagnosed by a physician as any of the following:

hyperkinetic, learning disability, learning disorder, overactive, hyperkinesis, minimal brain dysfunction, minimal brain damage, impulse disorder, hyperkinetic child behavior syndrome, minimal cerebral dysfunction?

(CROSS OUT THOSE INDICATED BY RESPONDENT.)

2. Of the remaining terms, would you consider them equivalent in meaning?

Yes _____ No _____

(IF NO): Please explain the differences for me? (LISTEN TO TAPE AND SUMMARIZE LATER.) _____

3. Based on the information contained in the literature and your own clinical practice, what do you consider the nature of the condition to be? (AFTER INTERVIEW, LISTEN TO THIS SECTION OF THE TAPE AND WRITE IN THIS SPACE A SUMMARY OF THE ANSWER TO THIS QUESTION.) _____

(PROBE:) a) What are the symptoms of the condition?

4. What do you think is the etiology of the condition? (AFTER INTERVIEW, LISTEN TO THIS SECTION OF THE TAPE AND WRITE IN THIS SPACE A SUMMARY OF THE ANSWER TO THIS QUESTION.) _____
- _____
- _____
- _____

5. If I were a parent whose child was diagnosed by you as hyperkinetic (OR TERM OF CHOICE), how would you explain this condition to me? (AFTER INTERVIEW, LISTEN TO THIS SECTION OF THE TAPE AND WRITE IN THIS SPACE A SUMMARY OF THE ANSWER TO THIS QUESTION.) _____
- _____
- _____
- _____

In both the lay and medical literatures assertions and conclusions about the nature of hyperkinesis (OR TERM OF CHOICE) have been put forth. Here is a sample of typical statements. Would you please indicate whether you agree or disagree with them?

- AGREE _____ DISAGREE _____ DON'T KNOW _____ 6. At least some cases of hyperactivity are caused by a physiological, neurological, or other medical disorder.
- AGREE _____ DISAGREE _____ DON'T KNOW _____ 7. At least some cases of hyperactivity are caused by psychological or emotional problems.
- AGREE _____ DISAGREE _____ DON'T KNOW _____ 8. At least some cases of hyperactivity are caused by poor nutrition.
- AGREE _____ DISAGREE _____ DON'T KNOW _____ 9. At least some cases of hyperactivity are caused by poor social conditions.
- AGREE _____ DISAGREE _____ DON'T KNOW _____ 10. At least some cases of hyperactivity are caused by food additives.

- AGREE ___ DISAGREE ___ DON'T KNOW ___ 11. At least some cases of hyperactivity are caused by poor schools or teachers.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 12. At least some cases of hyperactivity are caused by lead poisoning.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 13. The term "hyperactive" is used to characterize children who are energetic, active, creative, or merely restless.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 14. In some instances, it may be a good thing for a child to be hyperactive.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 15. The term "hyperactive" is used by people to make it possible for them to control or suppress children.
- AGREE ___ DISAGREE ___ DON'T KNOW ___ 16. The term "hyperactive" is a legitimate diagnosis of a real problem for some children.
17. What is the typical length of time that children stay on medication for hyperactivity?
- Don't know _____
- There is no typical regimen, i.e., too variable to say _____
- A few weeks _____
- A few months _____
- One to 14 years _____
- Until puberty—adolescence _____
18. There is widespread discussion of the efficacy of stimulant medication for hyperkinesia (OR TERM OF CHOICE). What do you think is the efficacy of stimulant medication?

(AFTER INTERVIEW, LISTEN TO THIS SECTION OF THE TAPE AND WRITE IN THIS SPACE A SUMMARY OF THE ANSWER TO THIS QUESTION.)

- (PROBE:) a) What kinds of efficacious outcomes can result from stimulant medication?
- b) What proportion of hyperkinetic children are helped by stimulant medication?
- c) To what extent does stimulant medication relieve the symptoms of hyperkinesis?

19. What side effects can (not necessarily will) stimulant medication produce?

(USE CHECK LIST)

_____	headaches	_____
_____	loss of appetite	_____
_____	stomachaches	_____
_____	insomnia	_____
_____	weight and height deficit	_____
_____	irritability	_____
_____	restlessness	_____
_____	other _____	_____

20. Have you heard or read criticism of stimulant medication for hyperactive children?

Yes _____ No _____

a) (IF YES): Could you briefly summarize the essential nature of these criticisms?

b) (IF YES): Could you briefly indicate how you would respond to the criticisms?

CHILD INTERVIEW SECTIONS: AWARENESS OF MEDICATION
PROCEDURE IN TAKING MEDICATION
RESPONSES OF OTHERS TO CHILD
SELF ESTEEM

AWARENESS OF MEDICATION: Child (Treated)

AIM: The purpose of this section of the interview is to determine how conscious the child is about his medical regimen. In some cases the child may be taking medication rather unconsciously. In other situations the child may not be taking medication even though his parents say that he is.

1. Are you (or have you*) taken any medicine or pills to help you at school or at home? (ADOPT CHILD'S LANGUAGE FOR PILLS OR MEDICINE FROM THIS POINT ON.)

Yes _____ No _____ Don't know _____

PROBE QUESTIONS TO BE ASKED IF "NO" OR "DON'T KNOW" TO QUESTION 1.

PROBE QUESTIONS: Is (was*) there any medicine or pills that the doctor gave you that you take in the morning and at lunch? Is (was*) there any medicine or pills that the doctor gave you that you don't take? Does (did*) your teacher or someone at home ever give you some medicine or pills?

(IF PROBE QUESTIONS ARE USED SUMMARIZE RESPONSE HERE.)

2. Do you know why you take this medicine or pills? Why?

3. Do you know what this medicine is? _____

4. How does it help you? _____

(LISTEN CAREFULLY TO DETERMINE HOW AWARE CHILD IS THAT HE IS TAKING MEDICATION FOR HYPERACTIVITY. EVEN IF THE CHILD IS FACTUALLY IN ERROR ABOUT THE NATURE OR USE OF MEDICATION - IT IS AWARENESS PER SE TO BE EVALUATED.)

Interviewer Rating for Awareness of Medication

- ☐ Very aware of the use of medication
- ☐ Aware after probing
- ☐ Child is aware medication was prescribed but is not taking it (or didn't take it)
- ☐ Child is not aware he is taking medication

(IF THE LAST CATEGORY IS CHECKED GO TO SELF ESTEEM SECTION AND END INTERVIEW AFTER THAT SECTION.)

*Past tense should be used for termination phase.

5. (ASK OF INITIATION AND TERMINATION CHILDREN ONLY.)
What grade were you in when you (started) (stopped) taking medicine?

6. Who was your teacher at that time?

7. What school were you at then?

NATURE OF PROBLEM AND NATURE OF TREATMENT: Child (Treated)

AIM: The purpose of this section of the interview is to find out how much the child knows about the problem that led to medication and the nature of the medication.

QUESTIONS ON PROBLEM:

1. Has anyone explained to you about why you take this medicine or pills?
Yes _____ No _____

1a. (IF YES) Who? _____

1b. What did they say? _____

2. Do you have any other ideas about why you take this medicine? What problems were you having? (RECORD A SUMMARY OF THE RESPONSE.)

3. Why are you taking pills or medicine? What's the most important thing (reason)?

☐ Anger control (mean, mad, fights)
☐ Anxious, nervous, upset
☐ Hyperactive (score only if child volunteers term)
☐ Calms me down
☐ Get along better with friends
☐ Get along better at home
☐ Improve school work
☐ Other _____
☐ Don't know _____

4. Do you feel any different after you take the medicine or pills?

☐ Yes ☐ No

- 4a. (IF YES) How do you feel after you take the medicine?

5. (ASK ONLY IF CHILD IS STILL BEING TREATED) How long do you think you'll be taking medicine?

☐ Until summer; 1 year or less
☐ 1-2 years
☐ 2-3 years
☐ More than 3 years
☐ Until behavior changes
☐ Until doctor says not to
☐ Don't know

6. Is there a certain word or name that doctors use for people that are taking medicine like yours?

☐ No
☐ Yes - hyperactive
☐ Yes - brain damaged
☐ Yes - other _____
☐ Don't know

(RATE THE CHILD'S UNDERSTANDING OF THE NATURE OF THE MEDICATION.)

☐ Much
☐ Some
☐ Little
☐ None

PROCEDURE FOLLOWED IN TAKING MEDICATION: Child (Treated)

AIM: The purpose of this section is to find out what the child knows of the procedures and check on the procedures directly by asking the child when, how and where medication is taken and if medication holidays occur.

1. When, during the day - what time - do (or did) you take your pills or medicine? Do (did) you take it: (ASK EACH OF THE ITEMS BELOW)

Don't (didn't) take them at all _____ (IF THIS, SKIP TO NATURE OF PROBLEM AND TREATMENT)

In the morning before school	_____ Yes	_____ No
In the morning at school	_____ Yes	_____ No
At lunch time at home	_____ Yes	_____ No
At lunch time at school	_____ Yes	_____ No
Right after school	_____ Yes	_____ No
Before supper	_____ Yes	_____ No
After supper	_____ Yes	_____ No
At night	_____ Yes	_____ No

2. Who gives you your pill or medicine at school or at home?

(NOTE: IF NOT TAKEN AT SCHOOL OR HOME, WRITE NONE ON THE BLANK. ASK BOTH ITEMS.)

at home? _____

at school? _____ (IF NOT TAKEN AT SCHOOL, SKIP TO QUESTION 3.)

- 2a. FOLLOW-UP QUESTION: (IF CHILD REPORTS TAKING MEDICATION AT SCHOOL:)

How does (did) the medicine or pill get to school?

PROBE QUESTION: (USE THIS ONLY IF QUESTION 2A IS NOT ANSWERED) Who brings (brought) it to school?

child _____

parent _____

other (specify) _____

- 2b. Where in the school do (did) you take the medicine or pill?

PROBE QUESTION: (USE THIS ONLY IF QUESTION 2b IS NOT ANSWERED) In what room or office?

classroom _____

nurse's office _____

principal's office _____

school office _____

hall _____

different places _____

other (specify) _____

3. When was the last time (date and time) you took a pill? _____

4. Do you take the medicine or pills every day? Yes _____
No _____

4a. (IF NO TO QUESTION 5) When do (did) you take the medicine or pills?

5. Are there ever any days you don't take your medicine or pill? Yes _____
No _____

5a. (IF YES) When ? _____

6. Do you take your medicine or pills on:
weekends Yes _____ No _____
Christmas vacation Yes _____ No _____
summer vacation Yes _____ No _____
Easter vacation Yes _____ No _____

7. Do you ever forget to take your medicine or pills? Yes _____
No _____

7a. (IF YES): How often? lots _____
hardly ever _____
never _____

8. Some children take their medicine or pills each time only when a grown-up tells them to. Is (was) this the way you take your medicine?
Yes _____ No _____

8a. (IF YES): Who tells you?

mother	Yes _____	No _____
father	Yes _____	No _____
brother or sister	Yes _____	No _____
doctor	Yes _____	No _____
teacher	Yes _____	No _____
other (specify)	Yes _____	No _____

9. Do you sometimes take more or less medicine when you're feeling a certain way—or when you're about to go somewhere or do something?

No _____
Yes—more (how many? _____)
Yes—less (how many? _____)
Alters timing—takes earlier _____ takes later _____
Don't know _____

9a. (IF YES) Who decides—and how? _____

RESPONSES OF OTHERS TO CHILD: Child (Treated)

AIM: The purpose of this section of the interview is to determine if the child has received any positive or negative feedback from others (parents, siblings, friends, teacher) as a result of stimulant medication usage.

1. Do other children ever say anything to you about the medicine you take?

☐ Yes
☐ No

- 1a. (IF YES) What do they say? _____

2. Do other children treat you unfairly because you take medication?

☐ Yes
☐ No

- 2a. (IF YES) What do they do? _____

3. Do other children ever tease you about it?

☐ Yes
☐ No

- 3a. (IF YES) What do they say? What do they do? _____

4. Do your brothers or sisters or parents ever say anything about the medicine you take?

☐ Yes

☐ No

- 4a. (IF YES) What do they say? _____

5. Do your brothers or sisters ever treat you unfairly because you take medicine?

☐ Yes

☐ No

- 5a. (IF YES) What do they do? _____

6. Do they ever tease you about it?

☐ Yes

☐ No

- 6a. (IF YES) How? _____

7. Do grown-ups ever say anything about the medicine you take?

☐ Yes

☐ No

7a. (IF YES) What do they say? _____

SELF ESTEEM: Child (Treated)

1. Everybody has some things about him which are good and some things about him which are bad. Are more of the things about you ...
☐ Good
☐ Bad
☐ Both about the same
2. Another kid said, "I am no good." Do you ever feel like this? (IF YES, ASK): Do you feel like this a lot or a little? "I am no good?"
☐ No
☐ A lot
☐ A little
3. A kid told me: "There's a lot wrong with me" Do you ever feel like this? (IF YES, ASK): Do you feel like this a lot or a little? "There's a lot wrong with me."
☐ No
☐ A lot
☐ A little
4. Another kid said: "I'm not much good at anything." Do you ever feel like this? (IF YES, ASK): Do you feel like this a lot or a little? "I'm not much good at anything."
☐ No
☐ A lot
☐ A little
5. Another kid said: "I think I am no good at all." Do you ever feel like this? (IF YES, ASK): Do you feel like this a lot or a little? "I think I am no good at all."
☐ No
☐ A lot
☐ A little
6. How happy are you with the kind of person you are? Are you ...
☐ Very happy with the kind of person you are
☐ Pretty happy
☐ A little happy
☐ Not at all happy

Appendix B

Guttman Scale Development

A GUTTMAN SCALE OF ATTITUDES TOWARD THE USE OF MEDICATION
IN THE TREATMENT OF HYPERACTIVE CHILDREN

Introduction

Samples of parents, teachers and physicians of hyperactive children were asked to signify whether they agreed or disagreed with eight attitudinal statements concerning the use of medication in the treatment of hyperactive children. These statements were designed to gain data which could be used to develop a composite measure of the respondents' attitudes toward the use of medications for these children. The statements, or items, are shown with the system of coding in Table I, which follows:

Table I
Statements Presented to Respondents

<u>Item No.</u>	<u>Description</u>	<u>Sense of Item</u>	<u>Original Coding</u>	<u>Revised Coding</u>
1	While medication necessary for small % of children, use too widespread	-	Agree = 1 Disagree = 2 Uncertain = 3	2 0 1
2	Most doctors careful in prescribing medication	+	Agree = 1 Disagree = 2 Uncertain = 3	0 2 1
3	So much confusion about hyperactivity, use of medication questionable	-	Agree = 1 Disagree = 2 Uncertain = 3	2 0 1
4	Not enough known about dangers of medication	-	Agree = 1 Disagree = 2 Uncertain = 3	2 0 1
5	Never proper to use medication to tamper with minds of children	-	Agree = 1 Disagree = 2 Uncertain = 3	2 0 1
6	For children who need them, medicines almost a miracle	+	Agree = 1 Disagree = 2 Uncertain = 3	0 2 1
7	Shame to let children suffer	+	Agree = 1 Disagree = 2 Uncertain = 3	0 2 1
8	Medication not total solution	+	Agree = 1 Disagree = 2 Uncertain = 3	0 2 1

Examination of the items in Table I reveals that the "sense" of items 1, 3, 4 and 5 is reversed relative to items 2, 6, 7 and 8. Therefore, the coding of these items was revised to give all items the same "sense." At the same time, the "uncertain" category was inserted between the "agree" and "disagree" categories. As revised, an item score of "0" signified the most favorable attitude toward medication for that item, while an item score of "2" signified the least favorable attitude.

Objectives

The primary objective is to construct a Guttman Scale of attitudes toward the use of medication in the treatment of hyperactive children. A suitable scale will have a Coefficient Reproducibility of at least 0.90 and a Coefficient Scalability of at least 0.60, and such a scale will include as many of the items of Table I as consistent with minimally obtaining these coefficients. Finally, these coefficients must be minimally obtained for each sample, i.e., the 179 parents, the 82 teachers, the 51 physicians and the combined sample of 312 respondents.

Initial Procedure

All scaling procedures are based on the use of the Guttman Scaling Subprogram contained in the "Statistical Package for the Social Sciences."

Our initial attempts at scaling the data considered only the combined sample of all respondents ($n = 312$). As it turned out, this was a mistake since physicians seem to have uniquely different attitudes with respect to some items. For example: They have a disbelief in "miracles." (Some of these attitudes should probably be evaluated individually across the various samples.)

The first three passes of the data from the combined sample were for the purpose of establishing "cutting points."

In Pass 1, the "uncertain" category was combined with the "disagree" category irrespective of the "sense" of the items. It yielded a Coefficient of Reproducibility of 0.84.

In Pass 2, the "uncertain" category was included with the "agree" category for items 1, 3, 4 and 5 and with the "disagree" category for items 2, 6, 7 and 8. This yielded a Coefficient of Reproducibility of 0.82.

In Pass 3, the "uncertain" category was included with the "disagree" category for items 1, 3, 4 and 5 and with the "agree" category for items, 2, 6, 7 and 8. This yielded a Coefficient of Reproducibility of 0.85. Pass 3 was tentatively accepted as the optimum procedure for coding.

Most of the non-scale errors occurred with item 1, which had 66 errors in Pass 3. Removal of this item resulted in a Coefficient of Reproducibility of 0.88 and a Coefficient of Scalability of 0.51. Neither of these coefficients meet the criteria defined as an objective.

The second highest source of non-scale errors occurred with item 5, which had 65 errors. Removal of items 1 and 5 resulted in a Coefficient of Reproducibility of 0.90 and a Coefficient of Scalability of 0.56. Again, these coefficients do not minimally meet our requirements. With these items removed, items 2, 4 and 6 show the greatest number of errors with item 2 having 42 errors, item 4 having 41 errors and item 6 having 38 errors. With item 2 removed, we obtained the highest coefficients with a Coefficient of Reproducibility of 0.925 and a Coefficient of Scalability of 0.678. While these coefficients are satisfactory, it was found that these items and cutting points did not yield satisfactory coefficients for the physician sample. Accordingly, we found it necessary to reapproach the entire problem by optimizing the selection of items to insure adequate coefficients for the physician sample.

Final Approach to Scaling Problem

Since the data from the physician sample did not yield satisfactory coefficients, we found it desirable to keep an eye on results from the data on both the combined sample of all respondents and the physician sample, as we went through the process of item selection. Table II below summarizes the process followed in determining which items to include in the final scale. (See Insert A)

Table II
Sequence of Steps in Developing a Guttman Scale of
Attitudes Toward Use of Medication in the Treatment of Hyperactive Children

Scale No.	Items Included	All Respondents* (n = 312)		Physicians (n = 51)	
		Coeff. of Reproducibility	Coeff. of Scalability	Coeff. of Reproducibility	Coeff. of Scalability
1	1 thru 8 (all)	0.8429	0.4357	0.8533	0.4066
2	1,2,3,4,5,7,8	0.8562	0.4891	0.8758	0.4737
3	1,3,4,5,6,7,8	0.8600	0.4941	0.8820	0.4648
4	1,3,4,5,7,8	0.8783	0.5656	0.9130	0.5714
5	3,4,5,7,8	0.9053	0.6471	0.9217	0.6000

*Includes: 179 Parents
82 Teachers
51 Physicians

Cutting Points (All Items): 0 = 0
1 }
2 } = 1

Since the results obtained with Scale 5 minimally meet the required criteria, this configuration was selected for the final scale. Results for each of the samples are shown in Table III.

Table III

<u>Sample</u>	<u>Coeff. of Reproducibility</u>	<u>Coeff. of Scalability</u>
All Respondents(n = 312)	0.9053	0.6471
Parents (n = 179)	0.9119	0.6842
Teachers (n = 82)	0.9012	0.6117
Physicians (n = 51)	0.9217	0.6000

Items Included in Scale: 3,4,5,7,8 Cutting Points:

0 = 0
1,2 = 1

Using the revised coding of Table I and the cutting points described in Pass 3 (and consistently used thereafter), descriptive statistics were obtained for each item for each sample. Individual item scores were summed for each item selected for the final scale configuration and a score established for each respondent. Again, descriptive statistics were obtained for this overall attitude score for each of the samples, as well as for the combined sample (see appropriate data books).

Insert A

All items were included in the preliminary scale construction, using the physician data. Table II, Scale 1, summarizes the results obtained on the physician sample of 51 observations and the combined sample of 312 observations. Examination of the scale errors associated with the physician sample indicates that items 2 and 6 each contribute 10 non-scale errors and contribute the most errors to the scale. For the combined sample of 312 observations, however, these items did not contribute the greatest number of non-scale errors. For the combined sample, items 5 and 1 each contributed greater numbers of errors than items 2 and 6, with 70 and 68 errors as compared with 52 and 57 errors, respectively. Nonetheless, the immediate goal was to improve the scalability of the physician data; therefore, items 6 and 2 were selected for deletion.

Scale 2 of Table II summarizes the effect of deleting item 6 while Scale 3 summarizes the effect of deleting item 2. For the physician sample, deletion of item 6 (Scale 2) results in item 2 showing up with the greatest number of errors (10) while deletion of item 2 (Scale 3) results in item 6 showing up with the greatest number of errors (9). For the combined sample, deletion of item 6 (Scale 2) or of item 2 (Scale 3) did not shift the order of errors, with items 1 and 5 contributing the most errors. Again, since the emphasis was placed on the physician data, items 2 and 6 were selected for simultaneous deletion. The results are summarized in Scale 4 of Table II.

Examination of Table II, Scale 4, indicates that for the physician data, deletion of both items 2 and 6 results in a scale which has a satisfactory Coefficient of Reproducibility, yet is somewhat marginal on scalability. On the other hand, the results for the combined sample yield neither a satisfactory Coefficient of Reproducibility nor a satisfactory Coefficient of Scalability. The emphasis must be placed on improving the results obtained using the data of the combined sample.

Insert A (Cont'd)

Examination of the scaling errors for Scale 4 of the combined sample indicates that item 1 contributes the most non-scale errors (62) when items 2 and 6 are not included in the scale. Therefore, item 1 was selected for deletion.

Scale 5 of Table II yields satisfactory coefficients for both the physician sample and the combined sample. The deletion of items 1, 2 and 6 minimally result in a scale satisfying the requirements; however, this does not infer that other approaches would not also yield satisfactory results. It would, of course, be possible to obtain higher coefficients by deleting additional items, but this was not deemed desirable because, as items are removed, the ideational content of the scale is likely to undergo undesirable change.

2

Appendix C

Interviewer Training

TENTATIVE OUTLINE FOR INTERVIEWER
SELECTION AND TRAINING PROCESS

I. Interviewer, selection process

A. Contact (30-35) people (Jack and Debbie)

1. Interviewer characteristics:

- a. age: late 20's to early 40's
- b. sex: female
- c. high academic standing, excellent references, and if possible, relevant work experiences.
- d. do not substitute teach in Grand Rapids Public Schools

B. Initial contact made by Jack Halteman and Debbie Wagner

- 1. Brief explanation of reason for contact
- 2. Set up interview with prospective employee March 21, 22, 23

C. Interview with prospective employee

1. Initial selection conducted by Jack Halteman

2. Content of interview:

- a. gather information on transportation capabilities, time availability, and willingness to commit energies to working on the project. Finally, assess most recent experience on similar activities or other activities which involve working with people.
- b. gather this information on a form plus most recent reference(s)
- c. explain following:
 - 1. working conditions involved
 - 2. remuneration for work
 - 3. nature of people they will interview
- d. decision on clearly acceptable or unacceptable candidates

3. Questionable potential interviewers referred to Drs. Bosco or Robin for decision

- a. form letter sent to unacceptable prospects
- b. notify acceptable interviewers and confirm hire (25-35)
- c. set up details of hiring with Mary

II. Interviewer training process consisting of three days in length with two sessions per day of two hour length:

Session 1, Group 1: 8:00 to 10:00 a.m.

Group 2: 10:00 to 12:00 noon

Session 2, Group 1: 1:00 p.m. to 3:00 p.m.

Group 2: 3:00 to 5:00 p.m.

Self instructional period:

Group 1: 10:00 to 12:00 noon

Group 2: 1:00 to 3:00 p.m.

Day 1, Session 1

1. Personal introductions with description of role in project
2. Description of nature and purpose of study (Drs. Bosco and Robin)
3. Description of samples in study
4. General ethical conduct and social etiquette (Jack)
5. Examination of legal forms
6. Self Instructional Session: Listen to sample parent and teacher interviews

Day 1, Session 2

1. Six crucial interviewer activities:
 - a. explanation of how initial contact will be made to set up interview (Jack)
 - b. asking the questions (Jack)
 - c. probing techniques (Jack)
 - d. question clarification techniques (Jack)
 - e. feedback techniques and non-recorded activities (Jack)
 - f. the interviewer as expert problem
 - g. list emergency phone numbers for interviewers, and Social Security Numbers
 - h. interviewers will do a 3-minute impromptu interview

Day 2, Session 1

1. Introduction to tape recorders
2. Introduction to interview schedules
3. Specific training for Parent Schedule

Self-Instructional Session: Read through all interview schedules

Day 2, Session 2

1. Specific training for Teacher Schedule
2. Interviewer practice on parent and teacher schedule
3. Possible cull of interviewers

Day 3, Session 1

Interviewers will practice interview with each other. Staff will switch periodically between groups and evaluate interviewers.

Self-Instructional Session: continue practice interviews and play back and critique

Day 3, Session 2

1. Explain logistics
2. Answer any questions
3. Final Comments from Bosco and Robin
4. Final Selection

INTERVIEWER'S MANUAL

1. Each week--or as necessary--you will stop at the Center for Educational Studies and pick up the interview packets with your name on them, for that time period (date is written on packet along with time of interview for that day). Check out when your interviews are during the day.
2. Call in, after you have checked your packets for interviews, to see if there have been any cancellations; and to double-check times and who is to be interviewed when. Make sure all necessary forms are in the packets assigned to you.
3. It is very important that each day, before you leave for any interviews, that you check the condition of the batteries in your tape recorder. Your INTERVIEWER'S LOG will assist you in keeping track of when you must change the batteries. It is imperative that each interview be recorded, so a beginning-of-the-day equipment check should become a habit.
4. At the end of each interview, make sure what needs to be written down is written; again check batteries. Fill in INTERVIEWER'S LOG with interviewee's name and time, and initial when you changed batteries.
5. You will have 3 extra packets of each interview protocol (total of 18) information form to keep at home. If you discover a piece of information is missing from one of your interview packets, you have extra copies to replace the missing information. It is important that you check out each packet BEFORE you do the interview so you know that you have all necessary forms. You may need a packet if we must schedule an interview during the week after you have received the packets for that week.
6. At the end of each day, return the interview packets to CES and make note of any interviews not completed on your INTERVIEWER'S LOG, as well as all interviews completed; and change of batteries. This LOG is to be turned in at the end of the week with the packets to Western Michigan University by way of the CES. Keep in mind any interviews not completed, and when you call in next morning tell Mary or Gail about it so the interview can be rescheduled as soon as possible. Make sure all information is enclosed in the envelope: all interview schedule forms and the cassette tape in its box.
7. If there are any questions about procedures, don't hesitate to phone in and ask.

TOLL FREE NUMBER:

1-800-442-4255

1-383-8157

SUPPLEMENTARY INFORMATION FOR INTERVIEWERS

Definition of Phases

The research study will divide the treatment of hyperkinetic children into three phases: Initiation, Monitoring, and Termination. For each of the respondents (parents, teachers, and physicians), interview schedules will be used which correspond to each of these three phases. Initiation is defined as the phase comprised of those children who have been treated with stimulant medications for six or less months. In other words, if you find that a child has been treated with stimulant medication since September, a period of eight months as of this writing, the phase would not be Initiation. Termination is comprised of those parents, teachers, and physicians of children who have ended medication treatment within the last six-month period. Monitoring is comprised of all situations which fall between these two phases.

Pronunciation Guide

Ritalin: rit'ə līn

Cylert: sī' lert

Dexedrine: dək' sə drēn

Dextroamphetamine: dək' strō ăm fed'ə mēn

What To Do If . . .

During the training session, we described a series of situations which may present themselves to you and described some ways of handling them. We would like to review that for you.

1. The interviewee asks you for your opinion on one of the questions that you have just asked. In this situation, you may find it useful to use this response:

"I really haven't had the type of experience that would allow me to develop an opinion about that."

Or, you may use this as a convenient point to mention the session that is being set up with medical, educational, and research personnel, wherein the opinions and beliefs of other experts might be sought.

2. Person expresses strong concerns or expresses a need for more information or help on some specific issue or the general situation. In this situation you can provide the information about the sessions that are being set up and suggest that this might be a place to start trying to find the help that is desired.

3. The respondent expresses concern or discusses the problem with you that has nothing to do with the substance of the interview, has some complaint about the school system, or some other situation. At no time should you advise the respondent about how to proceed with this complaint or problem, but explain that you know nothing about this and you're sorry that you can't be of help, you certainly understand how the respondent feels.
4. The interviewee provides a response which is too terse or brief for you to understand it sufficiently to make a response on the schedule. In this situation, you might say:

"Can you say a little more about this?"

Or, you might restate the ending words of the respondent in question form.

Or, you might develop a probe from the item itself, asking it without changing its meaning in a different way a second time.

5. It seems to you that the interviewee has not understood the question and is either groping for a response or has provided a response which clearly is not an answer to the question you have asked. In this situation you might say something like:

"Have I made the question clear?"

or:

"Let me try to clear up what I meant by that question."

or:

"I don't think I made that question clear enough. Let me try again."

6. If you find the need to provide some sort of response to an answer, you are encouraged to use expressions like:

"I see." "I understand." or "Uh Huh."

Marginal Comments

The interviewer should make any notes in the margin if it seems that a response of the interviewee requires some degree of clarification in order for it to be understood. If, for example, the interviewee adds some qualifications, or if the interviewee feels uncomfortable with the response categories provided, then this should be noted on the interview schedule.

The Use of Response Categories

Throughout the interview schedule there are categories set up for you to check or for you to use as a basis for summarizing the response that has been provided. You need not read these responses if the interviewee seems able to deal with the response and begins talking in a way which will provide for categorization. If it seems necessary, these response categories could provide a stimulus for the interviewee's response. If you find it necessary to use the response categories to "prime the pump", you should be sure to read a few of them, rather than just one. If you read only one or two, it may lock the interviewee into a narrow response.

Multiple Child Interviews

When you are interviewing teachers, you may have more than one child per teacher. In such a situation it will be necessary for you to go through the items that relate to the particular child for each child taught by the teacher. In some instances this may be across phases. You might have a teacher with three pupils in our sample, two of whom are in the Initiation Phase and one of whom is in the Monitoring Phase. You need only collect Background information once for the teacher. You would run through Events, Process, and Role Behavior three times; Assessment of Treatment three times; and Specific Attitude three times. The information on General Attitude, Role, and Beliefs would be dealt with only once.

Background Information

It will be necessary for you to go through the Background section, Page 2, of each interview. You will not be able to copy this from the Confidential Fact Sheet.

Name of Persons Being Interviewed

You will note that we request you to obtain the name of the persons who are participating in the interviews as an initial question in Background. If more than one person is participating, you will need to note their names and they would both have to sign the Informed Consent Form. You will also note that we have provided that the tape recorder would be started after you take the names. When you are interviewing parents and want, at the end of the interview, to get the Permission to Contact Form signed, only one parent need sign that form, not both, even if you are interviewing both. If both want to sign it, that's fine; but only one signature is needed.

Adjunctive Therapy

We have made some rather substantial changes in the Adjunctive Therapy section of the interview schedule (by the way, the term, "Adjunctive Therapy" would not be a good term to use with the interviewee). In the section as it is now presented you will determine if any other treatments or procedures are being used in addition to stimulant medications. Then you will ask what types of treatments are being used. You should not read through the entire list, but simply put a check (✓) by those treatments or procedures which are mentioned spontaneously by the respondent. If some treatment or treatments which are not on the list are mentioned, then these should be written in in the "Other" space. For those treatments or procedures which are mentioned, you should obtain the other information by asking the question which serves as the heading for the additional two columns.

Role

We have made some changes in the Role Section which should go a long way towards making this section a much easier section of the instrument to administer. We have removed some of the problems from the lead items. We have incorporated the flavor or the nature of the item into the question that deals with the responsible person for the task that has been mentioned. We have simplified this by taking out some of the response categories that were found in Version 1 of this instrument. You should note that if several individuals are mentioned as having some degree of responsibility or involvement relative to this task, multiple checks should be used. In the event that multiple checks are used, it will be necessary to identify whether or not any one of the persons checked has major responsibility; or whether they are all equal in responsibility. Finally, it will be necessary to cover each of the participants in the triad. If the respondent spontaneously mentions all three of the persons in the triad (parent, teacher, and doctor), then it would not be necessary to ask any of the three questions in Section C. You would simply check (✓) the first response under each of these three questions: "Teacher already mentioned above, Doctor already mentioned above, Parent already mentioned above." If none of the three are mentioned spontaneously (it could happen that a person identifies a school social worker and does not say anything about teacher, doctor, or parent), then it would be necessary to ask all three of the questions in Section C to determine how the individual feels about the involvement of these three types of people relative to the specified task. All that involves is reading the three statements under Section C and recording the interviewee's response to each of the statements. If only one or two of the three persons in the triad have been mentioned, then it would be necessary to ask the questions in Section C that specify the persons not mentioned spontaneously above.

Appendix D

Pre-Study Report

HYPERKINESIS AND TREATMENT PREVALENCE IN A SAMPLE OF KALAMAZOO SCHOOLS:
A REPORT OF A PRELIMINARY STUDY

Stanley S. Robin
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Western Michigan University

James J. Bosco
Professor of Teacher Education
Western Michigan University

June 1977

A pilot study was conducted in Kalamazoo in December of 1976 to investigate the prevalence of diagnosed hyperkinesis and types of treatment among Kalamazoo school children. In no known school system in the United States had prevalence rates been specified. This research, funded by the U. S. Office of Education and the National Institute of Mental Health, sought to establish a prevalence rate, to understand the social context of stimulant medication, and was the basis for a larger study in Grand Rapids.

There has been much controversy about the extent of diagnosis of hyperkinesis and types of treatment prescribed. Estimates have ranged from 3% to 20%. Most estimates are educated guesses by clinicians or other "experts", rather than being based upon systematically collected data. Charges that there have been promiscuous diagnosis and treatment of hyperkinesis, particularly with stimulant medication, have been raised. Even among those who regard the diagnosis as medically legitimate and the treatment with stimulant medication as acceptable, there are fears that the rates of diagnosis are excessive. Thus, this research of prevalence within a school system is seen as extremely important for reducing the controversy and providing sound education for hyperkinetic children.

Although only two schools were used in the Kalamazoo system, it is hoped that the rates and information from these two schools be used to provide an idea about the situation in the school system. Some of the questions which are to be addressed are: 1) What are the prevalence rates for diagnosed hyperkinesis? 2) To what extent do prevalence rates based on parent information coincide with prevalence rates based on teacher information? 3) What is the frequency for different kinds of treatments for diagnosed hyperkinesis? 4) What is the prevalence for teacher-suspected hyperkinesis?

Permission was received from Kalamazoo Public School System to collect data from regular classrooms (special education classes were omitted) in two elementary

schools, Vine and Winchell. Questionnaires were mailed to all the parents of children in both schools to collect initial information about the prevalence of hyperkinesis. Questionnaires were also mailed to all the teachers in these two schools.

The rates of return for parents was 63%, for teachers, 67%. From Vine School the response rate for parents was 58%, and from Winchell School the response rate for parents was 67%.*

Parents of 3.4% of the children (14 children) indicated that their child had been diagnosed by a physician as having a learning or behavior problem identifiable as hyperactivity or hyperkinesis. The prevalence of diagnosed hyperkinesis in Vine School is 3.7% (7 children) and in Winchell School is 3.2% (7 children). Of the children who were diagnosed as hyperkinetic, 12 are currently being treated. Of the total number of children in the two schools, 2.9% (12 children) are being treated with stimulant medication--Ritalin, Dexadrine, or Cylert. In Vine School the percentage of children treated with stimulant medications is 3.7% (7 children); in Winchell School the percentage of children being treated with stimulant medications is 2.3% (5 children). The other forms of treatment reported are behavior modification, counseling, special diets, and medication of a non-stimulant type. Of those children diagnosed as hyperkinetic and currently being treated, 85.7% are reported by parents as being treated with stimulant medication, 50% treated with behavior modification, 50% with counseling, 21.4% with special diets and 42.8% with non-stimulant medication (such as Benadryl, Dilantin, Phenobarbital, Imprimine, Mellaril and others).

The comparable figures for Vine School are: 100% are treated with stimulant medication, 42.8% with behavior modification, 57.1% with counseling, 14.3% with special diets and 42.8% with non-stimulant medication. For Winchell School 71.4% are

* Since teacher questionnaires were anonymous, it was not possible to distinguish teacher returns by school.

treated with stimulant medication, 57.1% treated with behavior modification, 42.8% with counseling, 29% with special diets and 42.8% with non-stimulant medication.*

The percent of the student population in these schools diagnosed as hyperactive and treated with stimulant medication is relatively small in comparison to the allegations of critics found in the literature. For those children diagnosed the overwhelming preferred treatment is stimulant medication, and the medication of choice is Ritalin.

The teachers disclosed that approximately 4.3% (28 children) of children in their classes at the present time have been diagnosed by a physician as hyperkinetic. This is almost a one percent difference (.9%) between the reported prevalence by parents and the prevalence reported by teachers. The difference between the teachers' report of prevalence and the parents' report of prevalence is twenty-five percent; at these rates for every nine children reported as diagnosed as hyperkinetic by parents, twelve children would be so reported by teachers.

Teachers report a prevalence of treatment as follows: of those children currently being treated, 53.6% are being treated with stimulant medication; 7.1% are being treated with behavior modification; 35.7% with counseling; 7.1% with special diets and 3.6% with non-stimulant medication (such as Benadryl, Dilantin, Phenobarbital, Imprimine, Mellaril, and others); 3.6% with psychiatric treatment; 71.4% with remedial instruction and 3.6% by some unknown medication.*

A comparison of the parents' and teachers' reports about the modes of treatment of hyperactive children shows rather large differences. Although for both stimulant medication is reported as the most frequent medical treatment, the parents report it in 86% of the cases and the teachers in 54% of the cases. Similarly, behavior modification is reported by parents in 50% of the cases; but only in 7% of the cases by teachers. Assuming that the teachers and parents are largely reporting about the

* Treatments add up to more than 100% because some children are receiving more than one kind of treatment.

same children, the teachers do not know what the parents know about the treatment of the hyperkinetic children in their classrooms.

When the teachers were asked how many children in their classes they believed exhibited the symptoms of the hyperkinetic child behavior syndrome, teachers estimated that 8.5% (55 children) did so. This may indicate that the prevalence in elementary schools of diagnosed hyperkinesis may rise in the near future, if the teachers' perceptions are accurate. If they are not accurate, then the teachers' perceptions of the prevalence of hyperkinesis, or potential hyperkinesis, which is almost double that of diagnosed hyperkinesis as reported by the teachers and two and one-half times the reported prevalence by parents, reveals the need for teacher training in this area, since a child so regarded by his/her teacher, even if not diagnosed, may be treated in educationally and interpersonally inappropriate ways.

Fortunately, there is an external check on the validity of the teachers' perceptions. Included in the questionnaire to parents was a behavior rating scale designed to discriminate behavior which may be diagnosed as hyperkinetic (Conners Test for Hyperkinesis--Parent Form). A twenty-five percent sampling of parental reports of their children's behavior was tabulated. These data reveal that 7.8% of the school child population of the Winchell and Vine Schools have symptoms of hyperkinesis as reported by their parents. For Winchell School it is 8.5% and for Vine School it is 7.3%.

These data indicate that the perception of diagnosed hyperkinesis of the school teachers is somewhat higher than the parental behavior reports, but much closer than the prevalence rate provided by the parents. (This indicates a possible rise in the diagnosis and treatment of hyperkinesis for children in the Kalamazoo School System if these data are generalizable.)

TABLE I

Questionnaire Return Rate for Parents		
	Return Rate	
	N	Percent
Vine	188	58
Winchell	219	67
Not Identified	2	--
Total	409	63

TABLE II

Questionnaire Return Rate for Teachers		
	Return Rate	
	N	Percent
Teacher Questionnaires	22	67

TABLE III

Parents' Report of Prevalence of Diagnosed Hyperkinesis

	<u>Prevalence</u>	
	<u>N</u>	<u>Percent</u>
Vine	7	3.7
Winchell	7	3.2
Total	14	3.4

TABLE IV

Parents' Report of Proportion of School Children
Treated with Stimulant Medication

	<u>Children Treated</u>	
	<u>N</u>	<u>Percent</u>
Vine	7	3.7
Winchell	5	2.3
Total	12	2.9

TABLE V

Parents Report Prevalence of Modes of Treatment
For Children Diagnosed as Hyperkinetic

Type of Treatment	Vine and Winchell		Vine		Winchell	
	N	Percent	N	Percent	N	Percent
Stimulant Medication	12	85.7	7	100.0	5	71.4
Behavior Modification	7	50.0	3	42.8	4	57.1
Counseling	7	50.0	4	57.1	3	42.8
Special Diet	3	21.4	1	14.3	2	29.0
Non-Stimulant Medication	6	42.8	3	42.8	3	42.8
Megavitamin Therapy	-	-	-	-	-	-
Psychiatric Treatment	-	-	-	-	-	-

TABLE VI

Teacher Estimates of Children in Their Classroom
Diagnosed as Hyperkinetic

School Teachers	N	Percent
Vine and Winchell Teachers	28	4.3

TABLE VII

Teacher Report of Prevalence of Modes of Treatment
For Children Diagnosed as Hyperkinetic

Type of Treatment	N	Percent
Stimulant Medication	15	53.6
Behavior Modification	2	7.1
Counseling	10	35.7
Special Diet	2	7.1
Non-Stimulant Medication	1	3.6
Psychiatric Treatment	1	3.6
Remedial Instruction	20	71.4
Medication Unknown	1	3.6
Megavitamin Therapy	--	--

TABLE VIII

Teachers' Estimates of How Many Children Exhibit Hyperkinetic Symptoms

School Teachers	N	Percent
Vine and Winchell	55	8.5

TABLE IX

Estimate of Prevalence of Hyperkinesis: Conners Test
Parent/Parental Form

Conners Estimate			
	Both Vine & Winchell	Vine	Winchell
Sample Size	102	47	55
# of Cases	8	4	4
%	7.8	8.5	7.3

Appendix E

Quality Control - Interviewers

PROCEDURES FOR QUALITY CONTROL

1. Dr. Bosco, Dr. Robin, and Jack Halteman will supervise one group consisting of seven (7) interviewers each.
2. Interview review procedures:
 - a. first interview to be reviewed from beginning to end.
 - b. next two interviews to be reviewed intensely (2/3 to 1/2 of the interview).
 - c. after first week three interviews per week will be reviewed. Focus will be on key points in the interview schedule:

Parent and Teacher Interviews

- 1) first section: introduction--3 or 4 questions
- 2) events and process--all
- 3) assessment of problem--all
- 4) role (parent, teacher, physician)--beginning and end
- 5) attitude (general)--all
- 6) specific beliefs--3 or 4 questions
- 7) last question on specific beliefs

Child Interviews

- 1) first section--awareness of medication
- 2) second section--first 2 questions (procedure)
- 3) third section--all (nature of problem and treatment)
- 4) fourth section--questions 1 and 2 (events and process)
- 5) fifth section--(self-esteem scale)--all

3. For each interview, reviewed questions will be coded in the following manner:

CodeDefinition

- | | |
|----------------------------|---|
| 1. Correct Question Asking | Interviewer reads question either exactly as printed on the questionnaire or with minor modifications which do not alter the frame of reference |
|----------------------------|---|

<u>Code</u>	<u>Definition</u>
2. Incorrect Question Asking	Interviewer either significantly alters part of question, or omits part of question, or replaces question with own statement, or reads question that should have been skipped.
3. Probes or Clarifies Non-Directively	Interviewer either makes up in own words a probe which is non-directive, repeats all or part of either question, or respondent's answer in a non-directive manner, or confirms frame of reference for respondent correctly.
4. Probes or Clarifies Directively	Interviewer either makes up a probe which is directive, repeats question or respondent's answer incorrectly, gives a directive introduction, or confirms a frame of reference incorrectly.
5. Other Appropriate Behavior	Interviewer gives either acceptable task-oriented clarification or other appropriate feedback.
6. Other Inappropriate Behavior	Interviewer either interrupts respondent, or gives personal opinion, or records responses incorrectly on questionnaire.
7. Non-Recorded Activity	Interviewer either omits a question, or there is data missing.
8. Pace	Interviewer conducts interview either too slowly or too rapidly.
4. Identification of Specific Problems: Corroboration of problem areas among Dr. Bosco, Dr. Robin, and Jack Halteman.	
5. Termination of interviewers who are patently incompetent.	
6. Calling in of interviewers in cases of poor performance.	
a) interviewer self-identification of poor performance whenever possible.	
b) if poor performance is not easily identified by interviewer, problem areas will be discussed.	
7. After interviewer has been called in for poor performance, her next two interviews will be intensely reviewed. If problem area(s) persist, interviewer will be released.	
8. Letters with positive feedback sent during first and third weeks.	
9. Interviewers must call in each morning to Center for Educational Research, WMU to verify scheduled interviews, check packets, battery checks, etc. And for any instructions from Researchers.	
10. Dr. Bosco will be responsible for the distribution of tapes for Quality Control.	

April 11, 1977

INTERVIEW QUALITY CONTROL

1. Divide first interviews of each interviewer into three (3) groups, one each for Robin, Halteman, and Bosco.
2. The entire interview will be monitored.
3. Each interview will be rated with the attached rating form. If the interviewer is rated "discontinue", the interviewer will be terminated after concurrence of one other person. If the interviewer is rated "retrain", the interviewer will be contacted and the problems discussed. No other interviews will be scheduled until the retraining occurs. In such a case, the second interview will be monitored as a first interview. If the interviewer is rated "minor problem", these will be discussed with the interviewer.
4. The second and third interviews will be monitored extensively--but not word for word.
5. Subsequently, we will monitor two (2) interviews per interviewer per week.

INTERVIEWER NAME AND NO. _____

E5

REVIEWER _____

DATE OF INTERVIEW _____

<u>Problem Title</u>	<u>Major Problem</u>	<u>Minor Problem</u>	<u>Section</u>
ASKS QUESTION INCORRECTLY			
Reads main stem of question as printed, but modifies or incorrectly reads any response categories in the question (does not apply, therefore, to open questions, since they do not have response categories.)			
Either significantly alters main body or stem of question while reading it, or reads only part of it.			
Does not read question, but instead makes a statement about the response he anticipates.			
Asks a question which should have been skipped.			
Other (specify) _____			

PROBES OR CLARIFIES DIRECTIVELY			
Makes up a probe which is directive, limiting, or changing the frame of reference of either the question or the potential response.			
Either repeats question and/or response choices incorrectly or gives incorrect summary of respondent's response.			
Either interprets question by rewording it or confirms a frame of reference incorrectly.			
Other (specify) _____			

Major Problem	Minor Problem	Section
------------------	------------------	---------

OTHER INAPPROPRIATE BEHAVIOR

Interrupts respondent.		
Gives personal opinion or evaluation.		
Records response incorrectly or incompletely on interview schedule.		
Suggests answer to respondent.		
Exhibits other unacceptable behavior. (specify) _____		
Omits question incorrectly.		
Fails to probe after inadequate answer.		
Other (specify) _____		

PACE AND VOICE INFLECTION

Conducts entire interview too slowly.		
Conducts entire interview at right pace.		
Reads questions in a wooden, expressionless manner.		
Reads questions with voice dropped, so that they sound like a statement.		
Reads questions with inaudible voice.		
Does not assume role of directing interviewer.		
Other _____		

<u>Major Problem</u>	<u>Minor Problem</u>	<u>Section</u>
--------------------------	--------------------------	----------------

FAILS TO ACHIEVE AND MAINTAIN RAPPORT

Fails to put respondent at ease.

Fails to be friendly.

Communicates an "I only work here" attitude.

Other (specify) _____

OVERALL RATING

_____ Discontinue

_____ Retrain

_____ Minor Problems

_____ OK/Good

SECTION CODE:

B= Background

EV= Events, Process, & Role Behavior

SA= Specific Attitude

A= Assessment

R= Role

GA= General Attitude

SB= Specific Beliefs

QUALITY CONTROL OF INTERVIEWERS

As the quality and usefulness of the research data is so heavily dependent upon the quality of the interviewing of subjects, precise procedures needed to be set up and implemented. One of the most important factors in this procedure was the early concentration of reviewing of the interviews. For this process, a format was set up outlining the exact number of interviews to be reviewed and the manner in which it should be done. Dr. Bosco, Dr. Robin and Jack Halteman supervised this process.

After the review of the initial interview, from beginning to end, the next two interviews were reviewed at the rate of 1/2 to 2/3 of the entire interview. From that point on, three interviews per week were reviewed, with focus on key points of the interview, as outlined in the procedure. These questions were rated as to appropriate delivery by the interviewer so as to achieve the most accurate data with the least possible interviewer influence on responses.

Where problems were determined, interviewers were informed immediately so problems could be resolved as quickly as possible. In several cases, it was necessary to terminate the services of the interviewer. In some cases, discussion and retraining were sufficient to enable the interviewer to continue satisfactorily.

A comprehensive rating outline was constructed for use by reviewers, which specified the specific area in which a problem existed, such as incorrect phrasing or altering of questions, improper probing, inappropriate behavior or voice inflection. A weekly log was then maintained to make certain the proper number of interviews were reviewed and that any appropriate action was taken where deemed necessary, such as emergency reviews or calling in of the interviewer for consultation with the reviewer or researcher.

In the case of the physician interviews, it was determined by the co-researchers that they would not be in a position to conduct all such interviews. They therefore selected two individuals, with doctoral status, whom they felt would be the best qualified for handling the rapport desired for these contacts.

Appendix F

Parent Consent Form

CONSENT TO CONTACT FORM

I _____ parent (or guardian)
of _____ consent to the interview of
my child, his/her public school teacher of last year (1977-78 school year)
and current physician. The child, teacher, and physician will be interviewed
about the same information contained in this interview.

Signature - parent or guardian

Appendix G

Quality Control - Coding

ORIENTATION

BACKGROUND: To be presented by researcher(s) and/or administrator. The researchers are: Dr. Stanley S. Robin, Professor of Sociology and Director, Center for Sociological Research, and Dr. James J. Bosco, Professor of Education and Director, Center for Educational Research. The title of this research is: Social Context of Stimulant Drug Treatment. It is jointly supported by the National Institute of Mental Health and the U.S. Office of Education, Bureau of Educationally Handicapped. Data have been gathered in the Grand Rapids area through the cooperation and approval of the Grand Rapids Public School System. The purpose is to explore the attitudes and beliefs of teachers, parents and physicians, as well as the children themselves, about hyperkinesis and its treatment.

CONFIDENTIALITY: It is important that all data involved in this project be handled on a strictly confidential basis with all information remaining in this room and not discussed outside nor among coders. The anonymity of all subjects is essential. There must be no conflict with the Human Subject Committee requirements and DHEW regulations covering research involving human subjects. This is a primary requirement of people involved on all levels of this project.

ACCOMPLISHED TO DATE: Questionnaires were mailed to parents of all children in 50% of the Grand Rapids Schools, and also to teachers. All the questionnaires were coded and put into the computer for print-out on data sheets. From these returned questionnaires, 216 cases were determined to be positive (diagnosed hyperkinetic). Interviews were then set up with the parents and, where consent obtained from the parents, with the teachers, children and physicians. All but a few physician interviews have been completed. We are now ready to commence coding of the interviews (approximately 600).

QUALITY CONTROL: Accuracy in coding cannot be stressed too stringently. It is the link to proper analysis of the data. While we have some deadlines for completion in mind, coding without error will save considerable time and money in the long run. The nature of the work can be tedious but understanding of the importance of your part in the total picture, and periodic short breaks, can be valuable in accomplishing efficient coding. There will be accuracy checks made on all coding to uncover problems and errors. An attempt will be made to resolve same, but in case of continued poor performance, a coder will have to be terminated.

PERSONNEL INFORMATION: Prior to commencing work, each coder should complete either a P-016 (students) or P-006 (non-students) form, along with a proper withholding statement. Keep the office advised of any change in address or telephone number, or hours available.

DATA SUPERVISION: The coding supervisor will be responsible for all interview packets removed and returned to the files, making very certain that the numbers are in proper order and the proper data are inside the packets. The supervisor will also check the folders for the mark sense sheets for the proper information and contents. There will be a check list on the inside of each folder. Coding questions should be directed to the research administrator for resolution by her or researchers. A record of all problems and resolutions should be maintained.

QUALITY CONTROL: Mark sense sheets will be reviewed on a regular basis by the office staff and researchers to spot problem coding. Steps will be taken to correct problems with release of a coder if necessary. Initially, the first 3 interviews completed by each coder should be in turn coded by someone else and then compared.

I. Check for differences, resolving the following errors:

1. Mechanical.
2. Improperly resolved anomaly; should have questioned.
3. Inadequate code; code book change required.

II. Where coding in agreement, check at least 4 items on each interview page (or 8 per pair).

III. Note whether marks made properly and erasures adequate.

After 10-15 interviews have been coded, make a trial run through computer. This will possibly uncover any further required changes in the coding process.

At this point, it will most likely be sufficient to review one out of every four interviews coded.

STORAGE: All interview packets will be kept in cabinets in the Social Psych. Lab, room 2208A, and locked at all times when not in use. They are to be filed numerically by mast set number with each related interview (parent, teacher, child, physician) fastened together with a rubberband. The mark sense sheets will also be stored in these file cabinets. They will be filed in folders and kept in numerical order by the mast number which will be inscribed on each applicable folder tab. The room must be locked at all times.

The research administrator will be responsible for the carrying out of the foregoing procedures.

QUALITY CONTROL

CODING OF INTERVIEW SCHEDULES

[illegible]

CODER EVALUATION FORM

NAME _____

DATE _____

REVIEWED BY _____

RELIABILITY:

_____SPEED:

_____ACCURACY:

_____COOPERATION:

_____ABILITY TO LEARN QUICKLY/
UNDERSTAND THOROUGHLY:

_____FOLLOWS INSTRUCTIONS:

_____INSIGHT/CRITICAL?

_____COMMENTS:

RECOMMENDATION FOR FUTURE EMPLOYMENT:

CODING PROCEDURES

I. Basic Process (see flow chart)

A. Coding

1. Interviews are pulled in order designated by phase master list (A).
2. Supervisor goes through each interview and resolves any unusual problems, recording resolutions in the margins of the interviews and in the problem log (B).
3. Interviews are then given to the coders and recorded on packet check list (C). Returned packets are checked in on (C).

B. Problem resolution

1. Coders record any coding problems on the coder problem sheet (B₁), which remains with the interview packet until the mark sense sheets are filed. The coder prob. sheets are then filed in the coders ind. file.
2. Coded interviews with problems are placed in drawer 1b (single-coded) or drawer 4b (double coded) until such time as they can be resolved.
3. Resolutions are recorded in problem log (B), in the interview margin, on the coders problem sheet (B₁). Codebook changes are recorded on the codebook change form (D). Changes are done in all codebooks prior to coding the following day.
4. Problems that can't be resolved by coding supervisors are tagged with an orange card and Ann is contacted. The packet is placed in drawer 1c, labeled "problems for Ann". Those that seem particularly unusual remain in the drawer until the next meeting of the minds.
5. When problems are resolved and resolutions have been recorded the packet is placed in one of three places:
 - a. drawer 2b -- to be double coded
 - b. shelf 6b -- to be quality checked (single coded)
 - c. shelf 3b -- to be quality corrected on the overhead projector prior to double coded quality checking.

C. Quality Control

1. Single Coded

Quality checker goes through the interview and mark sense sheets page by page, looking for problem questions and possible places for error. A minimum of eight questions are checked on each sheet. Errors are recorded on the quality control sheet. (E)

2. Double coded

- a. The two sets of mark sense sheets are compared on the overhead projector. Discrepancies are circled in red pencil. Interviews are placed in drawer 5b -- to be quality checked.
- b. circled columns are looked up in the codebook and interview and the proper code is determined, and marked on the m.s. sheets. Errors are recorded on (E).

D. Re-filing

1. Quality checked interviews are refiled in cabinets.
2. Mark sense sheets are filed in appropriate folder in drawer 2a. and recorded on sheet (F) in the file.
3. The final column on check list (B) is filled in:
 ✓ and date = mss filed
 Q ✓ and date = mss used for quality check and have been discarded.

II. Special Situations

A. Wierd file

Any unusual situations to be taken into consideration are recorded on an anomolie sheet (G) and placed in the wierd file in drawer 2a. On occasion, an interviewer's lengthy statement is xeroxed and placed in the file.

B. Doctor role questions

1. In order to code phys. role questions in a consistant manner, a cross referenced physician list was formulated, listing all treated kids' set numbers, phases etc.
2. A physician role question prob. sheet was devised. (H). One set of double coded role questions was determined as the master. problem resolutions from the master were recorded in the problem log (B) and on (H). The master mark sense sheets are traced or copied instead of recoding each set of role questions individually.

C. Reclassified and Misclassified interviews

When the interview classfifation does not coincide with the interview schedule used bythe interviewer, it is recorded on the "Interview schedule anomolies" chart posted on the wall. Cases are cross referenced on to the appropriate interview phase coding lists (A).

INTERVIEW CODING LIST
PACKETS FOR CHILD TERMINATION

<u>FAMILY NUMBER</u>	<u>CHILD NUMBER</u>	<u>PHASE</u>
	173	ST
0065		
	170	ST
0066		
	210	SPT
0069		
	283	SPT
0070		
	145	SPT
0071		
	345	ST
0075		
	309	ST
0077		
	284	ST
0079		
	227	SPT
0081		
	356	ST
0084		
	190	SPT
0089		
	130	SPT
0090		
	184	SPT
0094		
	365	NT
0101		
	310	SPT
0102		
	262	ST
0103		
	148	SPT
0105		
	182	SPT
0107		
	269	NT
0115		
	451	ST
0117		
	135	SPT
0120		
	150	ST
0121		
	329	ST
0123		
	176	ST
0125		
	399	SPT
0127		
	352	SPT
0128		

309

INTERVIEW SCHEDULES

68

Time: Started _____
Finished _____

<u>Orig.</u>	<u>QC</u>
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9
10	10
11	11
12	12
13	13
14	14
15	15
16	16
17	17
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82	82
83	83
84	84
85	85
86	86
87	87
88	88
89	89
90	90
91	91
92	92
93	93
94	94
95	95
96	96
97	97
98	98
99	99
100	100

Date _____

Date _____

312

INTERVIEW PACKETS AND FOLDERS

[illegible]

[illegible]

G12

CODING OF INTERVIEW SCHEDULES

315

ANOMOLIES

Phase:

Phase

Set

Problem / Resolution

Date: _____

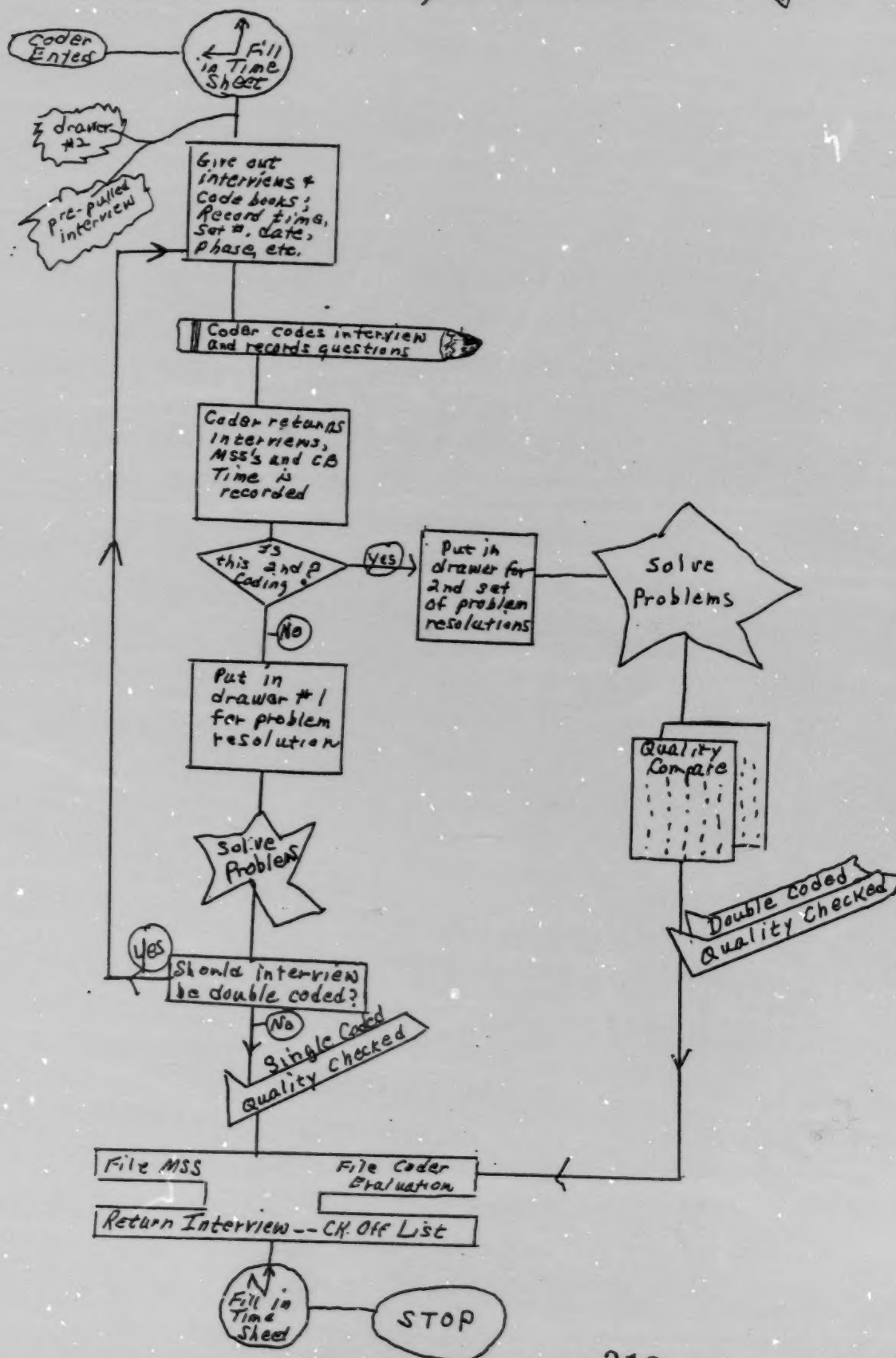
PhaseThis image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.[illegible]

5/11/78

SH

G15

Room Flow for Single & Double Coding



014-032			061-073			104-121			161-176		
033-045			074-087			122-138			177-192		
046-060			088-103			139-152			193-211		
1a	2a	3a	1b	2b	3b	1c	2c	3c	1d	2d	3d
Pos Question- naires	Mark Sense Sheets Coder Files		Single Coded	To be Double Coded	To Overhead Projector Compare ms	Problems for Ann		153-156		212-217	218-221
4a	5a	6a	4b	5b	6b	4c	5c	6c	4d	5d	6d
			Double Coded	Double Code To be Qual. Checked	Single Coded To be Qual. Checked			157-160			222 + Non. Pos.
319											320

Appendix H

Interviewer Oath of Confidentiality

This is to certify that I _____
will comply with the Federal guidelines and hold confidential all information
about and from Human Subjects as an interviewer in the Social Context of
Stimulant Drug Treatment research.

I will not divulge the identity of the Human Subjects, will keep confidential all statements made by the interviewees, and will hold confidential information about the interviewees. All information which is part of the interviewer's materials, i.e. interview schedules and all supplementary materials, Confidential Fact Sheet, and audio tape, will be kept secure and protected from access from all but the principal investigators and their designees. I will surrender these materials upon request of the principal investigators, or their agents, at the designated time and place.

Legal Signature

Appendix I

Kent County Medical Bulletin

level of citizenship responsibility."

He said he favored a mandated health care insurance for everyone with government paying for the "same ticket" for the unfortunate and needy. In addition to comments about government health care, he contended that the national welfare system needs to be totally overhauled.

"Physicians must be active to help decide what to do for whom, when and where," he advised.

Doctor Roy, who did his obstetrics-gynecology residency at Detroit General Hospital, is a former vice-speaker of the Kansas Medical Society House of Delegates.

— MSMS Department of Communications

NATIONAL INSTITUTE OF MENTAL HEALTH AND OFFICE OF EDUCATION AWARD LOCAL RESEARCH ON THE TREATMENT OF HYPERKINETIC CHILDREN

A research entitled, "Social Context of Stimulant Drug Treatment," sponsored by the National Institute of Mental Health and the U.S. Office of Education is currently being conducted in the Grand Rapids area. The researchers, Professor Stanley S. Robin and James J. Bosco of Western Michigan University are working with the Grand Rapids Public School System with Donald F. Waterman, M.D. and Dr. Edward Birch, Associate Superintendent for Special Education as consultants.

The purpose of the research is to specify the relationships among parents, teachers, and physicians in the treatment of hyperkinetic children with stimulant medication. The researchers will interview a sample of children in the Grand Rapids Public School System who are or were on a stimulant medication, their parents, teachers, and physicians. All interviews will be collected with the written consent of the parents and all information will be kept confidential.

The topic of the treatment of hyperkinetic children with stimulant medications has been a controversial and volatile topic. While there has been a considerable body of research on the nature of the condition and on the efficacy and toxicity of the treatment, there has been little, if any, calm objective research on the ways in which physicians, parents, and teachers interact and function together in the treatment of the hyperkinetic child. This research will explore the treatment of hyperkinetic children with stimulant medications from the perspectives of the parents, teachers, and physicians.

The researchers may be reached at 1-800-442-4255.

Appendix J

Chapter Five Tables

Table 5.1

J1

Responses of Grand Rapids Parents, Teachers and Physicians
About Processes of Problem Recognition for Hyperactive Children in Their Care

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Who first brought up the idea that child has a learning or behavior problem?						
Child's mother	2	18.18	1	8.33	3	30.00
Child's teacher	5	45.46	3	25.00	1	10.00
Child's father			1	8.33	1	10.00
Other school personnel	1	9.09	1	8.33	1	10.00
Former teacher	1	9.09	1	8.33		
Child's mother/father	1	9.09			1	10.00
Child's mother/father/teacher					1	10.00
Teacher/other school personnel			1	8.33		
Child's mother/teacher					2	20.00
Other	1	9.09				
Don't know			4	33.33		
Missing data	1					
Did you (parent, spouse, teacher, doctor) suspect any problem before this time?						
Yes	5	50.00	3	25.00	2	20.00
No	5	50.00	9	75.00	8	80.00
Missing data	2					
Who first brought up the idea that child needed professional help because of his/her problem?						
Child's mother	4	36.36				
Relatives	1	9.09				
Teacher	2	18.18				
Mother/father	1	9.09				
Other school personnel	1	9.09				
Other	2	18.18				
Missing data	1					
Did you make the decision that the child needed help because of his/her problem?						
Yes			5	41.67		
No			7	58.33		

Table 5.1(a)

J2

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
If no, did you take part in the decision to seek help for the child?						
Yes			2	28.57		
No			5	71.43		
Who first brought up the idea that child needed medical help?						
Child's doctor	1	9.09			1	10.00
Child's mother	4	36.36			3	30.00
Child's teacher	1	9.09			1	10.00
Other school personnel	1	9.09			2	20.00
Professional diagnostic organization	2	18.18				
Mother/father	1	9.09				
Other	1	9.09				
Father					1	10.00
Mother/teacher					1	10.00
Don't know					1	10.00
Missing data	1					
Did you make the decision to contact the doctor for medical help?						
Yes			1	8.33		
No			11	91.67		
Did you contact the doctor for help?						
No			12	100.00		
Were you the first person to bring up the idea that child needed medical help?						
Yes			1	8.33		
No			10	83.33		
Don't remember			1	8.33		
Did you contact child's parents for help?						
Yes			10	83.33		
No			2	16.67		

Table 5.1(b)

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Did you go to any other source inside or outside the school system for help for the child?						
Yes			9	75.00		
No			3	25.00		
Did you provide help for the teacher at the pre-diagnostic stage?						
Yes					3	37.50
No					5	62.50
No pre-diagnostic stage					2	
Did you provide help for the parents at the pre-diagnostic stage?						
Yes					4	50.00
No					3	37.50
Don't remember					1	12.50
No pre-diagnostic stage					2	

Table 5.2

Responses of Grand Rapids Parents, Teachers and Physicians
About Monitoring of Medication for Hyperactive Children in Their Care

Items and Responses	Parents (n = 42)		Teachers (n = 37)		Physicians (n = 37)	
	f	%	f	%	f	%
How often is child seen for a check-up for his medication?						
Once a month	4	9.76			2	6.67
6-11 times a year	1	2.44				
2-5 times a year	18	43.90			8	26.67
Once a year	16	39.02			14	46.67
Over 2 years between visits	1	2.44			1	3.33
Over 1, less than 2 years					4	13.33
Other	1	2.44			1	3.33
Missing data	1				7	
Do you conduct periodic examinations of child to monitor treatment?						
Yes					25	78.13
No					7	21.87
Missing data					5	
If yes, how are periodic examinations scheduled?						
Doctor schedules					17	68.00
Doctor contacts parent					2	8.00
Parent requests prescription refill					4	16.00
Parent thinks necessary					2	8.00
How do you know when it's time to go to the doctor for a check-up?						
Doctor schedules	10	24.39				
Doctor contacts	3	7.32				
Respondent requests prescription refill	14	34.15				
Respondent thinks necessary	10	24.39				
Doctor contacts/respondent requests prescription refill	2	4.88				
Respondent request prescript refill/ respondent thinks necessary	2	4.88				
Missing data	1					

Table 5.2(a)

Items and Responses	Parents (n = 42)		Teachers (n = 37)		Physicians (n = 37)	
	f	%	f	%	f	%
Has respondent or spouse had special visits with child's doctor because of problems or difficulties connected with the hyperactivity?						
Yes	16	39.02				
No	25	60.98				
Missing data	1					
If yes, how many of these special visits in the past <u>year</u> ?						
One	6	37.50				
Two	3	18.75				
Three	3	18.75				
Four	1	6.25				
None	3	18.75				
Does the parent provide the doctor with information to help him determine if the medication has side effects for child/does the doctor use the information from home to help in such determination?						
Yes	36	87.81			29	93.55
No	5	12.19			2	6.45
Missing data	1				6	
Does the teacher provide the doctor with information to help him determine if the medication has side effects for child/does the doctor use the information from school to help in such determination?						
Yes			7	19.44	23	76.19
No			29	80.56	8	25.81
Missing data			1		6	
Does the teacher provide, or the doctor obtain directly from the teacher, information in order to evaluate child's treatment?						
Yes			7	19.44	16	50.00
No			29	80.56	14	43.75
Don't remember					2	6.25
Missing data			1		5	

Table 5.2(b)

Items and Responses	Parents (n = 42)		Teachers (n = 37)		Physicians (n = 37)	
	f	%	f	%	f	%
If yes, what type of information was obtained?						
Written description					2	14.29
Verbal description					7	50.00
Written responses to specific questions					1	7.14
Evaluation (other professional school personnel)					1	7.14
Other					3	21.14
Missing data					2	
What kinds of tests and procedures were employed for the child's check-up?						
Neurological tests					2	6.25
Routine physical					9	28.13
General observation					1	3.13
Psychological tests					1	3.13
Neurological tests/routine physical					7	21.88
Neurological tests/history					1	3.13
Routine physical/general observation					3	9.38
Routine physical/blood work					1	3.13
Routine physical/history					1	3.13
Neurological tests/routine physical/history					4	12.50
Routine physical/psychological tests					1	3.13
Other					1	3.13
Missing data					5	
Does the parent provide the doctor with information to help in maintaining a dosage level of medication for child/does the doctor use the information from home in such determination?						
Yes	34	82.93			28	90.32
No	7	17.07			3	9.68
Missing data					6	
Does the teacher provide the doctor with information to help in maintaining a dosage level of medication for child/does the doctor use the information from school in such determination?						
Yes			6	17.14	19	61.29
No			29	82.86	12	38.71
Missing data			2		6	

Table 5.2(c)

Items and Responses	Parents (n = 42)		Teachers (n = 37)		Physicians (n = 37)	
	f	%	f	%	f	%
Does the teacher provide information about changes in child's behavior to help evaluate medication treatment/does the doctor use the information from the teacher in such evaluation?						
Yes			5	13.89	27	87.10
No			31	86.11	4	12.90
Missing data			1		6	
Was information obtained from other sources (school officials, scout leaders, relatives, etc.) about changes in child's behavior after medication was started?						
Yes	32	78.05	17	48.57	7	22.58
No	9	21.95	18	51.43	24	77.42
Missing data	1		2		6	
How often do the parents and teachers have meetings with each other to check up on how things are going with the child?						
Once a year	2	4.88	2	5.71		
Couple times a year	9	21.95	5	14.29		
3-4 times a year	8	19.51	9	25.71		
5-6 times a year	7	17.07	2	5.71		
7-11 times a year	3	7.32	1	2.86		
Once a month	3	7.32	3	8.57		
More than once a month	5	12.20	10	28.57		
When teacher calls	1	2.44				
When respondent thinks it is time	1	2.44				
Other	2	4.88	1	2.86		
Teacher thinks necessary/parent requests			1	2.86		
Never			1	2.86		
Missing data	1		2			
Does parent provide, or doctor use, information about child's behavior at home to evaluate treatment?						
Yes	37	92.50			31	100.00
No	3	7.50				
Missing data	2				6	

Table 5.2(d)

Items and Responses	Parents (n = 42)		Teachers (n = 37)		Physicians (n = 37)	
	f	%	f	%	f	%
In the past year, how many meetings have there been between the parent and teacher to discuss how things are going?						
None	1	2.44				
1	3	7.32	3	8.57		
2	11	26.83	4	11.43		
3	13	31.71	8	22.86		
4	2	4.88	8	22.86		
5	1	2.44	3	8.57		
6	3	7.32				
7	1	2.44	1	2.86		
8	3	7.32	1	2.86		
9	1	2.44				
10			3	8.57		
12			2	5.71		
14	1	2.44				
16			1	2.86		
67	1	2.44				
98			1	2.86		
Missing data	1		2			
On the average, how often during the year does the teacher meet with the parents of all of the children in his/her class?						
2			20	60.61		
3			9	27.27		
4			3	9.09		
8 or more			1	3.03		
Missing data			4			
Is information provided to the teacher about the child's condition and treatment to help the teacher do a better job in working with the child in the classroom?						
Yes	39	95.12			9	28.13
No	2	4.88			21	65.63
Don't remember					2	6.25
Missing data	1				5	

Table 5.2(e)

J9

Items and Responses	Parents (n = 42)		Teachers (n = 37)		Physicians (n = 37)	
	f	%	f	%	f	%
Has the parent, spouse, doctor consulted with new teachers at the beginning of the school year to help them relate to and teach child?						
Yes	35	85.37			5	16.13
No	6	14.63			25	80.64
Don't remember					1	3.23
Missing data	1				6	
Does parent serve as a channel of information between teacher and doctor?						
Yes	31	75.61				
No	9	21.95				
Don't know	1	2.44				
Missing data	1					
If yes, is the information usually spoken or written?						
Spoken	24	80.00				
Written	1	3.33				
Both	5	16.67				
Missing data	1					
Has the medication been stopped on a trial basis to see if the child still needs it?						
Yes	32	76.19	8	22.22	19	61.29
No	10	23.81	28	77.78	12	38.71
Missing data			1		6	
Has parent suggested to the doctor that medication be discontinued on a trial basis to see if child still needs it?						
Yes	13	30.95				
No	29	60.05				
Has teacher suggested medication be stopped on a trial basis to see if child still needs it?						
Yes			5	13.51		
No			32	86.49		

Table 5.2(f)

J10

Items and Responses	Parents (n = 42)		Teachers (n = 37)		Physicians (n = 37)	
	f	%	f	%	f	%
Has parent requested of the doctor that medication for child be ended?						
Yes	3	7.14				
No	38	90.48				
Don't remember	1	2.38				
Has teacher requested that medication for child be ended?						
Yes			3	8.11		
No			34	91.89		

Table 5.3

J11

Responses of Grand Rapids Parents, Teachers and Physicians
About Adjunctive Therapy for Hyperactive Children in Their Care

Types of Adjunctive Therapy That Were Currently or Previously Used	Parents (n = 48)		Teachers (n = 36)		Physicians (n = 26)	
	f	%	f	%	f	%
Types of adjunctive therapy that were currently or previously used:						
Counseling	14	29.14	8	22.22	9	36.00
Special diet	5	10.42	1	2.78	2	8.00
Changes in ways of reacting to child	6	12.50	2	5.56	1	4.00
Psychiatric treatment	4	8.33	1	2.78	2	8.00
Special education	7	14.58	5	13.89	6	24.00
Changes in home life	14	29.17	8	22.22	5	20.00
Changes in classroom procedures	12	25.00	16	44.44	2	8.00
Counseling for parents	5	10.42	3	8.33	4	16.00
Behavior modification	6	12.50	13	36.11	2	8.00
Other	8	16.67	10	27.78	6	24.00

Table 5.4
Responses of Grand Rapids Parents, Teachers and Physicians
About Processes of Diagnosis for
Initiation Phase of Hyperactive Children in Their Care

J12

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Were you informed of the child's diagnosis?						
Yes	10	83.33	11	91.67		
No	2	16.67	1	8.33		
If yes, by whom?						
Doctor	7	70.00	1	9.09		
School psychologist	1	10.00	1	9.09		
School social worker			1	9.09		
School nurse			1	9.09		
Parent			3	27.27		
Other professional	1	10.00				
School social worker/school psychologist			1	9.09		
Parent/other			1	9.09		
Teacher/school psychologist/principal	1	10.00				
Principal/parent/counselor			1	9.09		
Missing data			1			
Did the parents and doctor discuss the details and meaning of the child's diagnosis?						
Yes	8	72.73			9	100.00
No	3	27.27				
Not diagnosed					1	
Missing data	1					
How long (number of minutes) was the doctor's visit during which the diagnosis was made?						
10 min.	1	9.09				
12 min.	1	9.09			1	12.50
20 min.	2	18.18			3	37.50
22 min.	1	9.09				
30 min.	3	27.27			1	12.50
37 min.	1	9.09				
45 min.	1	9.09			1	12.50
90 min.					1	12.50
Can't remember/don't know					1	12.50
Other	1	9.09				
Missing data/no diagnosis	1				2	

Table 5.4(a)

J13

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Did you arrange a consultation with other medical specialists?						
Yes					2	20.00
No					8	80.00
Did you talk with the teacher about the child's behavior and learning in school to arrive at a diagnosis?						
Yes					1	11.11
No					8	88.89
Not diagnosed					1	
Did you request samples of child's school work, test results, observations, anecdotes or written reports from the teacher to help you make the diagnosis?						
Yes					4	40.00
No					5	50.00
Don't remember					1	10.00
Did the doctor receive samples of child's school work, test results, observations, anecdotes or written reports from the teacher to help you make the diagnosis?						
Yes			7	58.33	2	20.00
No			5	41.67	7	70.00
Don't remember					1	10.00
Did you talk to the doctor about the child's behavior at home?						
Yes	8	66.67				
No	3	25.00				
Don't remember	1	8.33				
Did the parent suggest the child might be hyperactive before the doctor made the diagnosis?						
Yes	7	63.64			2	22.22
No	3	27.27			4	44.44
Don't remember	1	9.09			3	33.33
Missing data	1				1	

Table 5.4(b)

J14

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Did you suggest that child might be hyperactive before the doctor made the diagnosis?						
Yes			2	16.67		
No			10	83.33		
Did you explain the child's diagnosis to other members of the family who were old enough to understand?						
Yes	6	75.00				
No	2	25.00				
No other family members	3					
Missing data	1					
Did you tell members of the school system about the child's diagnosis?						
Yes	12	100.00				
Did you conduct or have conducted any tests or other diagnostic or evaluative procedures in order to develop an understanding of the nature of the child's condition?						
Yes			1	8.33		
No			11	91.67		
Did you talk with the doctor about the child's behavior and learning in school?						
Yes			1	8.33		
No			11	91.67		
Did you record the medical diagnosis in child's cumulative record?						
Yes			1	9.09		
No			10	90.91		
Missing data			1			
Did you communicate child's medical diagnosis to others in the school system?						
Yes			7	58.33		
No			5	41.67		

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Were the teacher or other school personnel helpful in arriving at the diagnosis?						
Yes			8	65.67	4	40.00
No			4	33.33	6	60.00
Did the teacher and doctor discuss the details and meaning of the child's diagnosis?						
Yes			2	16.67	3	33.33
No			10	83.33	5	55.56
Don't remember					1	11.11
Not diagnosed					1	
Did you discuss the details and meaning of child's diagnosis/condition with child?						
Yes	7	63.64	6	50.00	5	50.00
No	4	36.36	6	50.00	4	40.00
Don't remember					1	10.00
Missing data	1					
Did the parents and teacher, or any other members of the school system, talk about the details and meaning of child's diagnosis?						
Yes	8	72.73	5	41.67		
No	3	27.27	7	58.33		
Missing data	1					
If yes, do you feel that your discussion with the teacher or other school personnel helped you understand more about child's condition or school situation?						
Yes	6	85.71				
No	1	14.29				
Missing data	1					
When child was being diagnosed, did you request consultation with one or more specialists in addition to your doctor?						
Yes	3	27.27				
No	8	72.73				
Missing data	1					

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Did you discuss the nature of child's condition with the class?						
Yes			1	8.33		
No			11	91.67		

Table 5.5

Responses of Grand Rapids Parents, Teachers, and Physicians
About Processes of Medication Treatment for Initiation Phase of
Hyperactive Children in Their Care

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Did you recommend use of medication?						
Yes	4	36.36	2	16.67		
No	6	54.55	10	83.33		
Don't remember	1	9.09				
Missing data	1					
If yes, was it a specific medication?						
Yes	2	50.00	1	50.00		
No	2	50.00	1	50.00		
Whose decision was it to use medication treatment for child?						
Doctor	4	36.36	5	41.67		
Parent	3	27.27	3	25.40		
Teacher	1	9.09				
Doctor/parent	1	9.09	2	16.67		
Doctor/parent/teacher	1	9.09				
Other	1	9.09	1	8.33		
Don't know			1	8.33		
Missing data	1					
Did you explain to household members old enough to understand why child is taking medication?						
Yes	8	66.67				
No	4	33.33				
Did you tell the teacher, others, in the school system, that child was being treated with medication?						
Yes	6	54.55	8	66.67		
No	5	45.46	4	33.33	9	90.00
Don't remember					1	10.00
Missing data	1					

Table 5.5(a)

J18

Items and Responses	Parents (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Did you record in child's cumulative record that he/she was being treated with medication?						
Yes			2	16.67		
No			10	83.33		
Were any other means of dealing with child tried before medication was begun?						
Yes	8	72.73	8	66.67	3	30.00
No	3	27.27	2	16.67	6	60.00
Don't remember			2	16.67	1	10.00
Missing data	1					
Was there any predisposition on the part of any adult in child's life to treat him/her with medication?						
Yes					4	40.00
No					5	50.00
Don't remember					1	10.00
Did you tell the teacher the child was being treated with medication?						
Yes	11	100.00			1	10.00
No					9	90.00
Missing data	1					
Did you talk to child about what medication is supposed to do for him/her?						
Yes	11	100.00	4	33.33	6	60.00
No			8	66.67	4	40.00
Missing data	1					
Has there been any change in the medication treatment of child since treatment began?						
Yes	6	50.00	3	25.00		
No	6	50.00	8	66.67		
Don't remember			1	8.33		
Do you give child's pill to him/her each time it is taken at home/school?						
Yes	9	81.82	1	8.33		
No	2	18.18	11	91.67		
Missing data	1					

Table 5.5(b)

J19

Items and Responses	Parents' (n = 12)		Teachers (n = 12)		Physicians (n = 10)	
	f	%	f	%	f	%
Where is medication kept at home/school?						
Medicine cabinet	1	11.00				
Kitchen	8	88.89				
Doesn't take at school			3	27.27		
Nurse's office			2	18.18		
Child's possession			2	18.18		
Teacher's possession			1	9.09		
Don't know			3	27.27		
Missing data	3		1			
Did you adjust or change the dosage or time when child takes his/her medication?						
Yes	5	41.67	1	8.33		
No	7	58.33	11	91.67		
Did you talk to child's parents about what the medication you prescribed for child is supposed to do?						
Yes					10	100.00
Do you know who sees to it that child takes his/her medication at school?						
Yes	7	87.50				
No	1	12.50				
Doesn't take at school	3					
Missing data	1					

Table 5.6

J20

Responses of Grand Rapids Parents, Teachers and Physicians
About Psychological and Social Support for Hyperactive Children in Their Care

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
Has the teacher or doctor attempted to provide child's parents with support and reassurance about their child?			(n = 93)		(n = 115)	
Yes			85	92.39	79	84.95
No			7	7.61	10	10.75
Don't remember					4	4.30
Missing data			1		22	
Has the teacher expressed any frustrations or feelings of difficulty to you about teaching child?			(n = 182)		(n = 115)	
Yes	99	55.62			22	23.40
No	79	44.38			62	65.96
Not in school when medication terminated	4					
Don't remember					10	10.64
If yes, have you tried to help teacher deal with these feelings?			(n = 99)		(n = 22)	
Yes	91	92.86			11	52.38
No	7	7.14			6	28.57
Don't remember					4	19.05
Missing data	1				1	
Has child been teased or made fun of because of taking medication?			(n = 167)		(n = 68)	
Yes	25	15.06	6	8.96	2	2.17
No	135	81.33	59	88.06	45	48.91
Don't know/remember	6	3.61	2	2.99	43	46.74
Other					2	2.17
Missing data	1		1		23	

Table 5.6(a)

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
Has child been teased at home because of his/her condition or treatment?	(n = 182)		(n = 68)		(n = 115)	
Yes	31	17.03	6	9.09	3	3.26
No	151	82.97	45	68.18	46	50.00
Don't know/remember			15	22.73	42	45.65
Other					1	1.09
Missing data			2		23	
If yes, have you done anything about it?	(n = 31)		(n = 6)		(n = 3)	
Yes	30	96.77	3	50.00	2	66.67
No	1	3.23	3	50.00	1	33.33
If yes, what has been done?	(n = 30)		(n = 3)		(n = 2)	
Nothing	2	6.45	3	50.00		
Worked with child	2	6.45				
Spoke to teaser	19	61.29				
Spoke to parents of teaser	2	6.45	2	33.33		
Disciplined teaser	4	12.90				
Worked with child/spoke to teaser	2	6.45				
Spoke to parents of child			1	16.67	1	50.00
Spoke to parents of child/ worked with child					1	50.00
Has child been teased at school because of his/her condition or treatment?	(n = 182)		(n = 80)		(n = 115)	
Yes	54	30.51	22	27.50	1	1.11
No	114	64.41	58	72.50	44	48.89
Don't know	9	5.09			45	50.00
Not in school when medication terminated	3					
Missing data	2				25	
If yes, did you do anything about it?	(n = 54)		(n = 22)		(n = 1)	
Yes	36	70.59	22	100.00	1	100.00
No	15	29.41				
Missing data	4				25	

Table 5.6(b)

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
If yes, what was done?	(n = 36)		(n = 22)		(n = 1)	
Talked to teacher	13	36.11				
Talked to principal	2	5.56	1	4.76		
Talked to child	5	13.89	3	14.29	1	100.00
Talked to others in school system	2	5.56				
Talked to teacher/principal	6	16.67				
Talked to teacher/child	5	13.89				
Talked to teacher/others in school system	1	2.78				
Talked to child/teacher/prin.	1	2.78				
Talked to/disciplined teaser	1	2.78				
Changed routine of child			1	4.76		
Talked to teaser			9	42.86		
Talked to class			5	23.81		
Talked to child/teaser			1	4.76		
Talked to parents of child/others in school system/teaser			1	4.76		
Missing data			1			
Do adults give child a "hard time" because he/she is taking medication?	(n = 167)		(n = 80)		(n = 115)	
Yes	13	7.78	2	2.53	2	2.20
No	154	92.22	73	92.41	48	52.75
Don't know			4	5.06	41	45.05
Missing data			1		24	
If yes, what has been done?	(n = 13)		(n = 2)			
Nothing	1	7.69	1	50.00		
Talked to adults	10	76.92	1	50.00		
Talked to school personnel	2	15.39				

Table 5.6(c)

J23

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
Has child had personal doubts or bad feelings that seemed to stem from the use of medication?	(n = 167)		(n = 80)		(n = 115)	
Yes	28	16.87	13	16.25	4	4.35
No	134	80.72	57	71.25	69	75.00
Don't know	4	2.41	10	12.50	19	20.65
Missing data	1				23	
If yes, have you helped the child deal with these doubts and feelings?			(n = 13)			
Yes			12	92.31		
No			1	7.69		
Have you joined or attended meetings of parents to discuss problems and hold rap sessions about their hyperactive children?	(n = 182)					
Yes	38	20.88				
No	144	79.12				
Have you gotten together informally with other parents of hyperactive children to share concerns and information?	(n = 182)					
Yes	72	39.56				
No	110	60.44				

Table 5.7

J24

Responses of Grand Rapids Parents, Teachers and Physicians
About Attitudinal Context for Hyperactive Children in Their Care

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
Has child been treated unfairly because of his/her diagnosis	(n = 182)		(n = 93)		(n = 115)	
Yes	64	35.16	12	12.90	3	3.16
No	116	63.74	76	81.72	54	56.84
Don't know	2	1.10	5	5.38	38	40.00
Not applicable-not diagnosed					5	
Missing data					26	
If yes, who treated child unfairly?	(n = 64)		(n = 12)		(n = 3)	
Parents	2	3.17	3	25.00		
Teachers	16	25.40	2	16.67	1	25.00
School personnel	5	7.94				
Other children	21	33.33	6	50.00	2	50.00
Relatives	4	6.35			1	25.00
Adult friends/neighbors	2	3.17				
Parents/other children	1	1.59				
Teachers/school personnel	2	3.17				
Teachers/other children	1	1.59				
Teachers/relatives	1	1.59				
Teachers/adult friends & neighbors	3	4.76				
Relatives/adult friends & neighbors	1	1.59				
Everyone	2	3.17				
Mother	1	1.59				
School personnel/other	1	1.59				
Parents/teachers			1	8.33		
Missing data	1					

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
Do you think child might have a better chance for success at school if his/her teachers and other school personnel did not know about his/her diagnosis and treatment?	(n = 182)		(n = 93)		(n = 115)	
Yes	25	14.12	16	17.39	4	4.26
No	136	76.84	67	72.83	69	73.40
Don't know	12	6.78	4	4.35	20	21.28
School personnel not informed	3	1.70	5	5.44	1	1.06
Other	1	0.57				
Not in school when medication terminated	3					
Not diagnosed					4	
Missing data	2		1		28	
Do you perceive any differences between your own and your spouse's attitude toward treatment?	(n = 167)					
Yes	29	23.58				
No	94	76.42				
No spouse	38					
Missing data	6					
If yes, name differences.	(n = 29)					
Both positive, spouse less positive	5	22.73				
Both positive, spouse more positive	1	4.55				
Both negative, spouse more negative	1	4.55				
Self positive, spouse negative	11	50.00				
Self negative, spouse positive	2	9.09				
Other	2	9.09				
Missing data	7					
Has the fact that child has been diagnosed as a "hyperactive child" seemed to make some people around him/her blind to child's other qualities?	(n = 182)		(n = 93)		(n = 126)	
Yes	78	42.86	14	15.22	8	8.68
No	96	52.75	75	81.52	47	51.09
Don't know	8	4.40	3	3.26	37	40.22
Not diagnosed					5	
Missing data			1		29	

Table 5.7(b)

J26

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
If yes, who tends to be this way?	(n = 78)		(n = 14)		(n = 8)	
Parents	4	5.41			2	33.33
Teacher	8	10.81	5	35.71	1	16.67
Physician	2	2.70	2	14.29		
Other children	9	12.16	1	7.14	1	16.67
Relatives	16	21.62			1	16.67
Adult friends/neighbors	6	8.11				
Parents/other children	1	1.35				
Parents/relatives	1	1.35				
Teacher/physician	1	1.35	3	21.43		
Teacher/relatives	5	6.76				
Physician/other children	1	1.35				
Other children/relatives	4	5.41				
Other children/adult friends & neighbors	3	4.05				
Other children/strangers	1	1.35				
Relatives/adult friends & neighbors	3	4.05				
Everyone	4	5.41	1	7.14		
Parents/other children/adult friends & neighbors	1	1.35				
Parents/other children/adult friends & neighbors/relatives	1	1.35				
Teacher/physician/relatives	1	1.35				
Teacher/physician/adult friends & neighbors/strangers	2	2.70				
Substitute teacher			1	7.14		
Physician/strangers			1	7.14		
Can't say for certain					1	16.67
Missing data	4				2	

Table 5.7(c)

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
Do you think child might be happier at school if others did not know about his/her diagnosis and treatment?	(n = 182)		(n = 93)		(n = 115)	
Yes	31	17.51	12	13.64	4	4.49
No	118	66.67	59	67.05	60	65.93
Don't know	20	11.30	10	11.36	27	29.67
School personnel, others, not informed	8	4.52	7	7.96		
Not in school when medication terminated	3					
Not diagnosed					4	
Missing data	2		5		31	
Do you think child might be happier at home if others did not know of his/her diagnosis and treatment?	(n = 182)		(n = 93)		(n = 115)	
Yes	25	13.74			5	5.49
No	147	80.77			75	82.42
Don't know	8	4.40			11	12.09
Others do not know	2	1.10				
Not diagnosed					4	
Missing data					31	
Do you think child benefits at school because school personnel know of his/her diagnosis and treatment?	(n = 182)		(n = 93)		(n = 115)	
Yes	141	78.77	60	65.93	65	71.43
No	28	15.64	14	15.39	8	8.79
Don't know	7	3.91	12	13.19	18	19.78
School personnel not informed	3	1.68	5	5.50		
Not in school when medication terminated	3					
Not diagnosed					4	
Missing data			2		31	

Table 5.7(d)

J28

Items and Responses	Parents		Teachers		Physicians	
	f	%	f	%	f	%
Do you think child benefits at home because the family knows of his/her diagnosis and treatment?	(n = 182)		(n = 93)		(n = 115)	
Yes	134	73.63			68	73.12
No	45	24.73			15	16.13
Don't know	3	1.65			10	10.75
Not diagnosed					4	
Missing data					29	

Table 5.8

J29

Responses of Grand Rapids Parents, Teachers and Physicians
About Termination of Medication

Items and Responses	Parents (n = 113)		Teachers (n = 31)		Physicians (n = 68)	
	f	%	f	%	f	%
Why was child's medication stopped?						
Child no longer needed medication	37	32.74	1	3.23	15	26.32
Medication doing no good	13	11.50			6	10.53
Parents didn't like idea of medication	16	14.16	3	9.68	4	7.02
Doctor didn't like idea of medication	7	6.20			1	1.75
Parents terminated medication					9	15.79
Child no longer needed medication/side effects too great					1	1.75
Child no longer needed medication/parents didn't like idea of medication					1	1.75
Child no longer needed medication/doctor didn't like idea of medication					1	1.75
Child no longer needed medication/parents terminated medication					1	1.75
Child no longer needed medication/other family or friends didn't like idea of med.					1	1.75
Medication doing no good/doctor didn't like idea of medication					1	1.75
Doctor-parents didn't like idea of med.	1	0.89			1	1.75
Child no longer needed medication/parents didn't like idea of medication/other					1	1.75
Doctor-parents didn't like idea of medication/ medication doing no good					1	1.75
Side effects too great	9	7.97	1	3.23		
Child didn't like idea of medication	2	1.77				
Teacher didn't like idea of medication	3	2.66	3	9.68		
Medication doing no good/side effects too great	3	2.66				
Side effects too great/parents didn't like idea of medication	2	1.77				
Parents didn't like idea of med./other	1	0.89				
Child no longer needed medication/child didn't like idea of medication	2	1.77				
Side effects too great/child didn't like idea of medication/other	1	0.89				
Child no longer needed medication/medication doing no good	1	0.89	1	3.23		

Table 5.8(a)

J30

Items and Responses	Parents (n = 113)		Teachers (n = 31)		Physicians (n = 68)	
	f	%	f	%	f	%
Why was child's medication stopped? (Cont'd)						
Medication doing no good/parents didn't like idea of medication	3	2.66				
Child-parents didn't like idea of medication	1	0.89				
Side effects too great/parents-teachers didn't like idea of medication			1	3.23		
Parents-doctor didn't like idea of medication	1	0.89				
Don't know			17	54.84	9	15.79
Other	11	9.74	4	12.90	4	7.02
Missing data					11	
Did you (parent, spouse, teacher or doctor) suggest that medication be ended?						
Yes	61	53.98	6	20.00	24	42.11
No	52	46.02	24	80.00	30	52.63
Don't remember					3	5.26
Missing data			1		11	
If yes, to whom?						
Parent	7	11.29	4	66.67	23	100.00
Teacher	7	11.29				
Doctor	37	59.68				
Teacher/doctor	6	9.68				
Teacher/doctor/other	1	1.61				
Teacher/other	1	1.61				
Parent/other school personnel			1	16.67		
Other	3	4.84				
Missing data			1		1	
Did you have an advance indication of when child's treatment would end?						
Yes					13	26.53
No					34	69.39
Don't remember					2	4.08
Missing data					19	

Table 5.8(b)

J31

Items and Responses	Parents (n = 113)		Teachers (n = 31)		Physicians (n = 68)	
	f	%	f	%	f	%
Did you (parent, spouse, doctor) make any special plans for the procedures for terminating child's medication?						
Yes	37	33.64			3	5.66
No	73	66.36			47	88.68
Don't know					3	5.66
Respondent did not terminate medication					1	
Missing data	3				14	
Did you try a trial discontinuation of medication as a method of finding if child's medication should be stopped/child no longer needed medication?						
Yes	57	50.89			26	52.00
No	55	49.11			22	44.00
Don't remember					2	4.00
Missing data	1				18	
Did you discuss with child the possibility that medication might no longer be needed?						
Yes	61	54.96	2	6.67	11	22.92
No	47	42.34	27	90.00	31	64.58
Don't remember	3	2.70	1	3.33	6	12.50
Missing data	2		1		20	
Was medication for child started again at any time after being stopped?						
Yes	11	9.74	4	13.79		
No	102	90.27	18	62.07		
Don't remember			7	24.14		
Missing data			2			
Did you collect information from the teacher in order to decide whether to stop the medication?						
Yes	55	50.93			15	27.78
No	51	47.22			37	68.52
Don't know	2	1.85				
Don't remember					2	3.70
Child not in school when med. terminated	5					
Missing data					14	

Items and Responses	Parents (n = 113)		Teachers (n = 31)		Physicians (n = 68)	
	f	%	f	%	f	%
Did child have any fears or doubts about stopping the medication?						
Yes	9	8.18	1	3.45		
No	101	91.82	18	62.07	28	65.12
Don't know					15	34.88
Don't remember			10	34.48		
Missing data	3		2		25	
Did you (parent, spouse, doctor) discuss ending medication treatment for child with his/her teacher?						
Yes	47	43.12			2	3.51
No	62	56.88			53	92.98
Don't remember					2	3.51
Child not in school when med. terminated	4					
Missing data					11	
Did you conduct a physical examination of child to determine if the condition was sufficiently improved to discontinue medication?						
Yes					13	26.53
No					36	73.47
Respondent did not terminate medication					1	
Missing data					18	
Did you make any changes in educational program or in your classroom's interaction with him/her after child ended medication?						
Yes			7	25.00		
No			20	71.43		
Don't remember			1	3.57		
Missing data			3			
Did you counsel/advise child's parents about ways of dealing with child after stopping medication?						
Yes			7	25.00	14	33.33
No			20	71.43	25	59.52
Don't remember			1	3.57	3	7.14
Missing data			3		26	

Table 5.8(d)

J33

Items and Responses	Parents (n = 113)		Teachers (n = 31)		Physicians (n = 68)	
	f	%	f	%	f	%
Did you collect information from the teacher in order to decide whether to stop the medication?						
Yes	55	50.93			15	27.78
No	51	47.22			37	68.52
Don't know	2	1.85				
Don't remember					2	3.70
Child not in school when med. terminated	5					
Missing data					14	
Did child have any fears or doubts about stopping the medication?						
Yes	9	8.18	1	3.45		
No	101	91.82	18	62.07	28	65.12
Don't know					15	34.88
Don't remember			10	34.48		
Missing data	3		2		25	
Did you (parent, spouse, doctor) discuss ending medication treatment for child with his/her teacher?						
Yes	47	43.12			2	3.51
No	62	56.88			53	92.98
Don't remember					2	3.51
Child not in school when med. terminated	4					
Missing data					11	
Did you conduct a physical examination of child to determine if the condition was sufficiently improved to discontinue medication?						
Yes					13	26.53
No					36	73.47
Respondent did not terminate medication					1	
Missing data					18	

Items and Responses	Parents (n = 113)		Teachers (n = 31)		Physicians (n = 68)	
	f	%	f	%	f	%
Did you try to find a time to end medication when child was not under a lot of pressure (i.e. exam time, holidays, when child is upset) or that involved a minimum of stress for child?						
Yes	42	39.25			18	50.00
No	65	60.75			14	38.89
Don't know					4	11.11
Respondent did not end medication					19	
Missing data	6				13	
Did you give directions to child's parents about the disposal of medication when the treatment was ended?						
Yes					3	8.82
No					30	88.24
Don't remember					1	2.94
No medication left					8	
Missing data					26	
Did you conduct a post-medication examination for monitoring long-range side effects of the medication treatment?						
Yes					15	27.78
No					39	72.22
Missing data					14	
If yes, what procedures did you use for the examination?						
Neurological tests					1	7.69
Routine physical					6	46.15
Neurological tests/routine physical					2	15.39
Other					2	15.39
Missing data					2	

Appendix K

Chapter Six Tables

Table 6.1

Scale Scores for Grand Rapids Parents, Teachers and Physicians on the
Instrument Measuring General Attitude Toward Medication for Hyperactive Children

Attitude Score	Parents (n = 177)		Teachers (n = 80)		Physicians (n = 46)		All Samples (n = 303)	
	f	%	f	%	f	%	f	%
0 = Most favorable	40	22.60	18	22.50	24	52.17	82	27.06
1	43	24.29	26	32.50	9	19.57	78	25.74
2	47	26.55	19	23.75	5	10.87	71	23.43
3	36	20.34	14	17.50	6	13.04	56	18.48
4	8	4.52	2	2.50	2	4.35	12	3.96
5 = Most opposed	3	1.70	1	1.25	-	-	4	2.43
$\bar{X}$	1.65		1.49		0.99		1.50	
SD	1.25		1.17		1.26		1.25	

Table 6.2

Scale Scores for Parents of Children in the
Initiation, Monitoring and Termination Phases on the
Instrument Measuring General Attitude Toward Medication for Hyperactive Children

Attitude Score	Initiation (n=12)		Monitoring (n=42)		Termination (n=113)		Untreated (n=15)	
	f	%	f	%	f	%	f	%
0 = Most favorable	4	33.33	10	23.81	23	20.91	3	20.00
1	4	33.33	16	38.10	23	20.91	2	13.33
2	1	8.33	8	19.05	32	29.09	6	40.00
3	2	16.67	8	19.05	24	21.82	2	13.33
4	1	8.33	-	-	5	4.55	2	13.33
5 = Most opposed	-	-	-	-	3	2.73	-	-
$\bar{X}$	1.33		1.33		1.76		1.87	
SD	1.37		1.05		1.28		1.30	

Table 6.3

Scale Scores for Kalamazoo Parents on the Instrument
Measuring General Attitude Toward Medication for Hyperactive Children

Attitude Score	Parents (n = 39)	
	f	%
0 = Most favorable	9	23.68
1	12	31.58
2	13	34.21
3	4	10.53
4	-	-
5 = Most opposed	-	-
$\bar{X}$		1.32
SD		0.96

Table 6.4
Child's Attitude Toward Medication

Item	Grand Rapids (n = 128)		Kalamazoo (n = 36)	
	f	%	f	%
Medication is a good thing	52	40.6	13	36.1
Some good/some bad	21	16.4	8	22.2
Medication is a bad thing	8	6.3	1	2.8
Don't know if it is good or bad	25	19.6	13	36.1
Child unaware	22	17.1	1	2.8

Table 6.5

General Attitudes of Grand Rapids Parents, Teachers and Physicians ..
Toward Medication for Hyperactive Children

Item	Parents (n = 179)						Teachers (n = 82)						Physicians (n = 51)					
	Agree		Disagree		Undecided		Agree		Disagree		Undecided		Agree		Disagree		Undecided	
	f	%	f	%	f	%	f	%	f	%	f	%	f	%	f	%	f	%
While the use of medication may be necessary for a small percentage of children, its use has become too widespread.	100	55.87	64	35.75	15	8.38	46	56.10	27	32.96	9	10.98	34	68.00	12	24.00	4	8.00
Most doctors are careful in prescribing medication and they work well for hyperactive children.	140	78.21	29	16.20	10	5.59	50	60.98	21	25.61	11	13.47	28	56.00	17	34.00	5	10.00
There is so much confusion about what hyperactivity is that the use of medication is questionable.	113	63.13	59	32.96	7	3.91	53	64.63	25	30.49	4	4.88	19	38.78	30	61.22	-	-
Not enough is known about dangers of medication to make it a safe approach.	82	45.81	87	48.60	10	5.59	26	32.10	44	54.32	11	13.58	12	24.00	37	74.00	1	2.00
It is never proper to use medication to tamper with the minds of children in school.	64	35.96	103	57.87	11	6.18	18	21.95	61	74.39	3	3.66	5	10.42	43	89.58	-	-
For children who need them, these medicines are almost a miracle.	142	79.33	30	16.76	7	3.91	53	64.63	19	23.17	10	12.20	33	66.00	15	30.00	2	4.00
It's a shame to let children suffer when there are medicines like these that can help them.	160	89.89	13	7.30	5	2.81	63	76.83	12	14.63	7	8.53	39	82.98	8	17.02	-	-
Medication is not the total solution for the hyperactive child, but it is a useful and important part of the solution	169	74.94	8	4.49	1	0.56	72	95.06	1	1.24	3	3.70	48	96.00	2	4.00	-	-

Appendix L

Chapter Seven Tables

Table 7.1
 Interviewer Rating of Child's Understanding
 of Medication Used in Treatment

	Grand Rapids (n =106)		Kalamazoo (n = 34)		Total (n =140)	
	f	%	f	%	f	%
Much understanding	43	40.57	11	32.35	54	38.57
Some understanding	29	27.36	16	47.06	45	32.14
Little understanding	24	22.64	6	17.65	30	21.43
No understanding	10	9.43	1	2.94	11	7.86

Table 7.2
 Child's Report About People
 Who Explained Medication to Child

	Grand Rapids (n = 104)		Kalamazoo (n = 34)		Total (n = 138)	
	f	%	f	%	f	%
No reported conversation	37	35.58	18	52.94	55	39.86
Conversations with:						
Doctor	20	19.23	9	26.47	29	21.01
Teacher	1	0.96	0	0.00	1	0.72
Parent	52	50.00	8	23.53	60	43.48
Nurse	2	1.92	0	0.00	2	1.45
Other professional	0	0.00	1	2.94	1	0.72
Don't know	1	0.96	1	2.94	2	1.45

Table 7.3

Child's Perception of Critical
Incident Leading to Decision to Medicate

	Grand Rapids (n = 61)		Kalamazoo (n = 30)		Total (n = 91)	
	f	%	f	%	f	%
No critical incident	15	24.59	8	26.67	23	25.27
Problems at school	15	24.59	4	13.33	19	20.88
Problems at home	9	14.75	1	3.33	10	10.99
Example of others taking medication	2	3.28	0	0.00	2	2.20
Learning or behavior problem	5	8.20	6	20.00	11	12.09
Bad dreams	1	1.64	0	0.00	1	1.10
Hurt self	1	1.64	0	0.00	1	1.10
Check-up	1	1.64	2	6.67	3	3.30
Other	0	0.00	2	6.67	2	2.20
Don't know	14	22.95	7	23.33	21	23.08

Table 7.4
 Child's Perception of Whose Idea
 It Was to Start Medication

	Grand Rapids (n = 106)		Kalamazoo (n = 34)		Total (n = 140)	
	f	%	f	%	f	%
Parents	40	37.74	8	23.53	48	34.29
Teachers and other school personnel	6	5.66	1	2.94	7	5.00
Physician	56	52.83	16	47.06	72	51.43
Self	3	2.83	0	0.00	3	2.14
Other family member	1	0.94	0	0.00	1	0.71
Other	1	0.94	2	5.88	3	2.14
Don't know	19	17.92	4	11.76	23	16.43
Child Guidance Clinic (Kalamazoo)			3	8.82	3	2.14

Table 7.5
 Child's Evaluation of Medication's Efficacy

	Grand Rapids (n =107)		Kalamazoo (n =34)		Total (n =141)	
	f	%	f	%	f	%
Helps very much	61	57.01	19	55.88	80	56.74
Helps some	32	29.91	11	32.35	43	30.50
Doesn't help	14	13.08	2	5.88	16	11.35
Don't know	0	0.00	2	5.88	2	1.42

Table 7.6
 Child's Assessment About Effect of Medication
 on Ability to be with Friends

	Grand Rapids (n = 107)		Kalamazoo (n = 34)		Total (n = 141)	
	f	%	f	%	f	%
Medication makes it more difficult to be with friends	21	19.63	10	29.41	31	21.99
Medication makes it easier to be with friends	66	61.68	18	52.94	84	59.57
Medication makes no difference	18	16.82	3	8.82	21	14.89
Don't know	2	1.87	3	8.82	5	3.55

Table 7.7
 Child's Assessment of Effect of
 Medication on Ability to do School Work

	Grand Rapids (n =107)		Kalamazoo (n =34)		Total (n =141)	
	f	%	f	%	f	%
Medication makes work more difficult	19	17.76	5	14.71	24	17.02
Medication makes work easier	60	56.07	22	64.71	82	58.16
Medication makes no difference	19	17.76	1	2.94	20	14.18
Don't know	9	8.41	6	17.65	15	10.64

Table 7.8
 Child's Report of Consequences
 of Not Taking Medication

	Grand Rapids (n =106)		Kalamazoo (n =34)		Total (n =130)	
	f	%	f	%	f	%
No discernible consequences	46	43.40	12	35.29	57	43.85
Negative psychological symptoms	19	17.92	6	17.65	25	19.23
Behavior problems .	9	8.49	5	14.71	14	10.77
Problems at home	4	3.77	0	0.00	4	3.08
Problems with school	10	9.43	1	2.94	11	8.46
Problems with friends	3	2.83	0	0.00	3	2.31
Become "hyperactive"	6	5.66	5	14.71	11	8.46
Get "sick"	2	1.89	0	0.00	2	1.54
Feel better	1	0.94	1	2.94	2	1.54
Feel different	1	0.94	0	0.00	1	0.77
Other	3	2.83	2	5.88	5	3.85

Table 7.9
Time and Place of Medication as Reported by Child

	Grand Rapids (n = 108)				Kalamazoo (n = 34)				Total (n = 142)			
	f	Yes %	Don't Know f	Don't Know %	f	Yes %	Don't Know f	Don't Know %	f	Yes %	Don't Know f	Don't Know %
In morning before school	86	79.63	5	4.63	33	97.06	0	0.00	119	83.80	5	3.52
In morning at school	12	11.11	5	4.63	2	5.88	0	0.00	14	9.86	5	3.52
At lunchtime at home	17	15.74	4	3.70	8	23.53	0	0.00	25	17.61	4	2.82
At lunchtime at school	67	62.04	3	2.78	26	76.47	0	0.00	93	65.49	3	2.11
Right after school	17	15.74	9	8.33	17	50.00	0	0.00	34	23.94	9	6.34
Before supper	8	7.41	6	5.56	3	8.82	0	0.00	11	7.75	6	4.23
After supper	9	8.33	5	4.63	3	8.82	0	0.00	12	8.45	5	3.52
At night	19	17.59	5	4.63	4	11.76	0	0.00	23	16.20	5	3.52
Other	0	0.00	0	0.00	4	11.76	0	0.00	4	2.82	0	0.00

Table 7.10
 Child's Report of Others'
 Reactions to Their Medication

	Grand Rapids (n = 104)		Kalamazoo (n = 33)		Total (n = 137)	
	f	%	f	%	f	%
Other children:						
Say nothing	71	68.27	13	39.39	84	61.31
Ask for information	15	14.42	8	24.24	23	16.79
Tease	15	14.42	9	27.27	24	17.52
Other	3	2.88	0	0.00	3	2.19
Don't know	1	0.96	3	9.09	4	2.92
Other children:	(n = 103)		(n = 33)		(n = 136)	
Treat child unfairly	20	19.42	16	48.48	36	26.47
Do not treat child unfairly	83	80.58	17	51.51	100	73.53
Other children:	(n = 104)		(n = 34)		(n = 138)	
Tease	27	25.96	13	38.24	40	31.25
Do not tease	77	74.04	21	61.76	98	71.01
Siblings:	(n = 95)		(n = 30)		(n = 125)	
Treat child unfairly	6	6.32	3	10.00	9	7.20
Do not treat child unfairly	89	93.68	27	90.00	116	92.80
Siblings:	(n = 95)		(n = 31)		(n = 126)	
Tease	11	11.58	4	12.90	15	11.90
Do not tease	84	88.42	27	87.10	111	88.10

Appendix M

Responses from Child Interviews

RESPONSES FROM CHILD INTERVIEWS

Why Medication is Taken

Helps me get better - family-wise.

My dad has nerves, my mom has nerves, and I have nerves.
My mom's, dad's are stronger than mine. They still got 'em.

I'm kind of off.

We take it only when we get mean and evil and your temperature goes up, and then you take one to cool you down.

I'm too annoying.

Because my friends and my cousins were. I sometimes..I get kinda crazy lookin' and I smash into my head, and the jaws on the chair and um... (You fall down?) Yeah, and hurt myself.

I talked to my parents and my parents told me that I have to take them, but I have an awful life, you know. I just go around being hyper as an ox. Well, I have an awful life. I go around as hyper as a tornado.

(Do you change your pills? Do you sometimes take more or less?)

It's not how I'm feeling. It's how, if I'm happy..it's how my mom is feeling about how the Ritalin is helping me. I'd rather not take it. I betcha I'd be just the same.

(If your mom decides that she thinks maybe, you said that it was your mom who decided. I think you said if she thinks your're happy, she..)

She doesn't give me it or doesn't give me as much. Like, well, if I'm acting good, she doesn't give me as much or doesn't even give it to me.

(Do you have any other ideas about why you take the medicine? What problems were you having?)

I was frightened a lot in kindergarten. But at kindergarten we went to () school and, see, they have up to 6th grade. And they all go out at the same time at recess there. That's a problem. The 6th graders are beating up on everybody. I don't mean going and threatening. It's threatening and doing it whether you did what they wanted you to do or not. Even if you did what they want, they'd still beat you up. I can remember on the monkey bars jumping on one of them.

Why Medication is Taken (Cont'd)

(So you can remember what you were doing in kindergarten and () school. Can you remember anything else that you were doing when you were taking the medicine?)

Umhmm. I wasn't taking it in kindergarten.

(I mean why you were taking it. What problems were you having when you started the medicine?)

A lot of fighting. I don't like to remember about kindergarten. It was an awful time. I felt like I was in World War II.

(Was there anything particular that got you started taking it... Was there anything that happened?)

Umhmm. I got in a lot of fights. I hadn't been doing my work cause I fight better when I'm tired. Cause when somebody makes me angry it just puts back my energy. And I have my energy cause I'm all awake. I've been using it up in working so I just save it inside when I don't take it. That's how I am now.

(So, they helped you. How did they help you; did they keep you out of trouble?)

Yea, they kept me out of trouble and I didn't speak that much so, um, I couldn't get into like - well, when I was on the pills if I kept on talking, you know, in a really -- I'd get in trouble sometimes and nobody could beat me up cause they had never heard my voice or anything. And if they'd call me a name I'd just, you know, shrug my shoulders, or whatever, and call it just later. (You liked being that way better?) Yea, I think.

What Happens if Child Forgets to Take Medication

I just get really, I act funny. I don't know what's happening to me. Like I hit people, like I just jump around and get my mom mad, you know, like that.

Attitude Toward Medication

It's a very nice thing. It's a very good thing. It's something to be proud of. Because you're a lot stronger than a lot of people who are older than you are. You're stronger than some of your friends. I'm the strongest one on the block because I'm hyperactive.

Effect of Medication

(Do other children ever say anything to you about the medicine you take?)

Yes. At school they call them hyper pills. (Does that bother you?) Only when they fool around like, "Ka, Ha, you take hyper pills," like that, and that's the only time it gets me really mad. Know what? When someone gets me in trouble, you know, they say, "Hey, Dave," and they're gonna be in a fight you know, and other people talk about it, you know, and the fight's gonna be in a few minutes, they go, "Hey Dave, did you take your hyper pills?"

(Who says that?)

James, I think, you know. And if I said yea, he's say, "Aw shoot. You would have tore him apart, if you didn't take them."

(So, they wanna know when there's gonna be a fight, huh?)

Yea. Because if I have a lot of candy, like loads of it, like a ton, and I didn't take my pill or drink any water, and guess what. I could tear someone's arm out of the socket if I wanted to. (You think you really could?) It's only an expression of speech.

(Does it seem harder to be with your friends when you're taking the medicine?)

No. It's never hard to be with friends. All I do is walk up to them. But it's hard to work with them; it seems that everyone is watching me, especially when I'm taking my medicine. You know what I mean? (I think so.)

(Can you think about that question again. Then see what you would choose on those answers.)

Well, if you mean when I'm in school and I take the Ritalin, you know, when I'm working, it's hard to be with friends because I know I'd rather do the work than be with friends, because I wouldn't just stand there and talk and it feels weird to do that. It's hard to do that. It's hard to do that in class. Because of you know what's gonna happen to you.

(When you forget to take your medicine, what happens?)

When I forget to, well, sometimes I get, you can make me aggravated very easily. Ane one time I forgot to have it and on purpose, because I knew that this kid wanted to fight. He wanted to settle it by fighting me after school. And I told my baby sitter, "Bonnie, I'm gonna have a fight with this kid first. Then you can give it to me." And I didn't even wait for an answer. I just jumped on my bike and rode off. And I came back and I won the fight.

Effect of Medication (Cont'd)

(And then you no longer took them in fourth grade?)
My mom says she wanted to quit because -- you're too quiet and stuff, and I don't want you and I don't like you like this. (Were you glad that she said that?) No. Because I like being quiet.

May I ask you a question? (Sure.) Like they said that stuff was dangerous because you'd have hallucinations like snakes crawling up your legs and stuff? I don't think I've ever heard that.

(Well, they've said a lot of different things and it's hard to know what to count on. I really don't know. I don't know much about it myself...actually, that's what we're doing this for, is to try and find out more about it so we can..) You can ask me all these questions all day, and I'll give you answers. (Good. You're really helping us. We have a lot of people who are helping us, and some people that really don't want to help us, so this is really nice.) I like talking to people and getting my feelings out. (Good.)

Communication with Others Regarding Medication

(Do grown-ups ever say anything about the medicine?)
Dr. () and some of the other doctors. (But how about uncles and friends, relatives?) Sometimes my cousins and aunts talk to my mom about it because it's an interesting subject and that's the first thing they think about because that's the way they start a conversation, getting interested in something, and that's very interesting - so my mom's a good conversation started. (What do they say.) They usually just talk about I'm playing with the relatives mostly.

(So, that helped you in school. Did you ask your teacher or you mom or your doctor any questions about being given the pills.)

I asked the doctor why I was on it and he goes, "Because you have a disease," and I thought, you know, the flu or some bugs inside of me. That's what I got, and I got scared and everything else. (Did you talk to your teacher or your mom?) About it? (Yes) I might have. I ain't that good of remembering, but I could have.

(Did you ever talk to them about changing the pills?)

One time I said, the first time I was taking them, I said, "I want to go on something else. I don't like them." And he said, "We'll find some. This isn't the only thing."

Teasing and Stigmatizing by Peers

The notion of stigma can be seen in the child's response to the question - (Do you talk to anyone?) Child responds: I kept it a secret.

Reports that his brothers tease him and say to him, "We don't have to take pills like you, fool."

They say, "Ha, ha, Eric has to have medicine." (This child was a 7 year-old boy.)

So, but like, you know, you take it at a drinking fountain, and they say, "Oh, I see Bill taking some pills," you know, and make funny, and say that you're taking drugs and stuff. They'd make a joke out of it.

(What did they say or what did they do when they were teasing you about it?)

Well, like I don't know how they found out. Some of them found out, you know, that I was supposed to be hyperactive. They found out from my sister. They say, "Joe's hyper," you know. It's pretty funny. They think it's funny. They didn't really bug me. Sometimes I get mad.

(Did you brother or your sister or your parents say anything about the medicine you took?) Umhmm. (And what did they say do you remember?)

Like when me and my brother and sister ever get in a fight, they used to say stuff like, you know, "Why don't you take one of your pills?" I don't know if they were saying this cause they're mad, they just want to, you know, hurt my feelings.

(Do other children ever say anything to you about the medicine you take?) Yes. (What do they say?) I don't want to say it. (Do other children treat you unfairly because you take medication?)

Yea, some. (What?) I don't want to say it. Does this go to my mom or dad? (No.) Where does it go to? (Western Michigan University. We've talked to a lot of other boys and girls too, and this is the way we can learn a lot of things about how you feel about taking the medicine.) I feel terrible.

(Do the other children ever tease you about taking the medicine?) Umhmm. (What do they say or do?) They just say mean things. I don't want to say them.

Teasing and Stigmatizing by Peers (Cont'd)

(Do your brothers or sisters or parents ever say anything?)
Not usually.

(Do your brothers ever treat you unfairly because you take the medicine?)

Oh yea! They also get...(What do they do?) Sometimes they'll say "pill freak" and they don't live very long. My brother's only six and...(Oh, they're younger brothers?) The other one's nine. (Do they ever tease you about it?) Yup. (How?) Just the way I said, but they're nice brothers.

(Do other children treat you unfairly because you take medication?)

Yes. (What do they do?) Call me names, and I don't like that because that's unfair. What did I do?

(Do other children ever tease you about it?)

Yes. (What do they say?) Well, they say "John is a hyper-head" or "You take pills." I know that. Why would I want to be reminded about them? They're stupid.

Maintenance of Regimen

Sometimes when I didn't want to take them, like at school, I'd throw them away, and not let my mom know about it.

(Do you sometimes take more or less medicine when you're feeling a certain way - or when you're about to go somewhere or do something?)

Well, actually, I've got to take my pills when I go someplace like to a relative's or camping, because I've gotta act my best so I won't get my dad mad when he's driving.

(While you were taking these, did you take them every day?)
Umhmm. Every day.

(And were there any days when you didn't take the pill? You mentioned one time when you forgot to. Were there any other times when you didn't? Like maybe skipped a day?)

No, wait a minute, I was late one time and hadn't had time to take my pill before I went to school...and the teacher, oh, I got so.. (They could tell, huh? Okay, time to go and get your pill and come back upstairs.)

(But most of the time you remembered pretty well.) Yea.

Teasing and Stigmatizing by Peers (Cont'd)

(Did you take it on weekends, Saturday and Sunday?)

Yea, I had to take them all the time.

(Every morning and..?)

Every morning and afternoon.

(Even when you went home for Christmas vacation?) Yea.

(And during the summer vacation, too...and probably during Easter vacation also?) Yea.

(Every morning you'd get up and take it either before or after breakfast?)

Yea. It's like you got a routine like when I get home, I gotta watch t.v. I know it's on. (part of your routine, right?)

Yea, so I, you know, I wake up and my mom smiles, and I say, "I'll be right back, mom, and I go and finish. (Yea, I think I know what you mean. Get into a routine and you don't forget too often.) Umhmm.

Etiology

(In what way does it help you?)

Well, if, like after. It's at the tip of my tongue. Um, when like I have something to eat, like, and I have to take that medicine because sometimes it doesn't really do that. Like if I have food, and I don't have the pills, I'll like act sort of funny. I'll get hyperactive. And if I have some foods that I can't have, I'll get hyperactive, too.

(So, you think the medicine is helping you? Do you know it helps you when you're hyperactive?) Yes.

(Do you think it has something to do with your food?)

Well, if I have something that's off my diet, I'll get hyperactive and if I don't get hyperactive yet, like I just had some chocolate cookies, and I was allergic to them, I'd drink a lot of water to dissolve it. Then I'd, like, barf, and then that would get rid of it.

Miscellaneous

(But the pills were changed. Whose idea was that?)

The doctor's. He went up there to a new field, and I think it was because of money. The brand new ones cost more.

(You think he wanted more money?)

The money. Because they was building some more things in the hospital.

(Who did you ever talk to about changing the pills or going on to something else?)

My mom.

Miscellaneous (Cont'd)

(What did she say about that?)

She said , "This is the best thing in the world; we'll see what we can know."

(Did you ever talk to any of them about stopping the pills?)

No, because I hadn't ever really thought of it.

(Whose idea was it to stop the medication?)

My mom. And the doctor decided, well, if you want coffee, there ain't no pills, and it don't cost that much.

(And he agreed?) Yea.

Appendix N

Chapter Nine Tables

Table 9.2

Distribution of Index of Agreement by Dyads

Parent/Teacher (n = 92), Parent/Physician (n = 125) and Teacher/Physician (n = 72)

Index Scores	Parent/Teacher		Parent/Physician		Teacher/Physician	
	f	%	f	%	f	%
80- 84	0	0	0	0	0	0
85- 89	1	1	0	0	0	0
90- 94	0	0	0	0	2	3
95- 99	0	0	0	0	1	1
100-104	1	1	2	2	2	3
105-109	2	2	3	2	4	6
110-114	1	1	4	3	0	0
115-119	5	5	8	6	4	6
120-124	4	4	8	6	2	3
125-129	7	8	7	6	9	13
130-134	5	5	7	6	3	4
135-139	7	8	10	8	9	13
140-144	4	4	7	6	11	15
145-149	12	13	13	10	3	4
150-154	10	11	16	13	5	7
155-159	6	7	12	10	2	3
160-164	7	8	5	4	5	7
165-169	5	5	8	6	2	3
170-174	3	3	7	6	0	0
175-179	4	4	2	2	6	8
180-184	3	3	2	2	0	0
185-189	1	1	2	2	1	1
190-194	1	1	1	1	0	0
195-199	2	2	1	1	1	1
200-204	1	1	0	0	0	0
$\bar{X}$	147.9		144.6		140.0	